

Clear Policy, Clear Conscience:  
Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

A Thesis Submitted to the College of  
Graduate Studies and Research  
In Partial Fulfillment of the Requirements  
For the Degree of Doctor of Philosophy  
In the Johnson Shoyama Graduate School of Public Policy  
University of Saskatchewan  
Saskatoon

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## **Abstract**

The creation of policies to mediate conscientious disagreements between healthcare professionals and those they serve presents a unique challenge for Canadian policy makers. As policies related to conscience issues are developed and refined, policy makers will need to investigate not only cases where conscientious disagreements have escalated into conflicts, but also the many situations and contexts in which healthcare professionals and their patients have been able to find positive resolutions. Such positive outcomes are frequently observed in palliative medicine. Palliative care teams throughout the world have earned a reputation for generating a high degree of patient and family satisfaction despite the teams' regular exposure to the end-of-life ethical challenges from which conscientious disagreements are likely to arise. My research used interviews and focus groups to bring description to the deliberative processes of the Saskatoon Health Region's palliative care team. These data were analyzed and presented to two interpretive panels, the members of which commented as to whether or not the processes described might be used to inform the development of a policy framework to facilitate the positive resolution of conscientious disagreements in other areas of the healthcare system. This policy framework holds the promise of promoting a culture of ethical awareness within healthcare institutions, thereby decreasing the moral distress experienced by healthcare professionals, minimizing the financial and emotional costs of protracted court cases, and enhancing the relationships between healthcare professionals and their patients.

## **Acknowledgements**

I have been incredibly blessed by colleagues, family and friends who encouraged me throughout the process of completing this dissertation. First, I wish to thank Dr. Keith Walker, who always saw three steps ahead to ensure my work went as smoothly as possible. Whenever I thought I had hit a roadblock, he was there to talk me through the problem, and I am immensely grateful for his expertise, enthusiasm and genuine care for my well-being. I also wish to thank my Advisory Committee, Dr. Lois Berry, Dr. Sheila Harding and Amy Zarzeczny, for their insights and wisdom.

I am indebted to the Sisters of the Presentation of Mary for allowing me to live with them for two years and providing me with the perfect environment in which to write my dissertation. Their stability kept me sane, and I will always be grateful for their guidance.

Finally, my research would not have been possible without the generosity of Dr. Vivian Walker, Meredith Wild and the Saskatoon Health Region's palliative care team. I have only captured a portion of the palliative care team's life-giving work in the pages of this dissertation, and I hope the exceptional care they provide to patients and families will serve as an example for others.

## **Dedication**

This work is dedicated to my parents. I owe them everything.

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## **Chapter One:**

### **Research Problem**

#### **Introduction**

When I completed my master's degree I realized that, after six years of studying bioethical theory, I needed to gain practical experience in the healthcare system before I would be able to continue my studies. To this end, I accepted a position as a hospital chaplain in an acute care facility in Western Canada. This hospital was relatively small for a tertiary care centre, but the centre housed the oncology and palliative care units for that region of the province and thus provided end-of-life care for a range of patients. Each of these patients entered the hospital with their own needs, opinions, beliefs, values and goals of care, which were not always aligned with the culture of care of the hospital or the healthcare professionals who cared for them.

During my time at this healthcare facility I realized that, at such ethically challenging times as the end of life, disagreements regarding care were unavoidable despite the best intentions of all involved. As a chaplain, my unique relationship with patients and staff often placed me in the middle of conversations about end-of-life care, which included decisions regarding the removal of ventilators, the use of artificial nutrition and hydration, and the long-term care placement of individuals who could no longer live independently. These situations led me to appreciate both the struggles of patients and families who are faced with life-altering decisions as well as the deeply personal and professional challenges facing hospital staff who strive to provide exceptional care. I observed that, during ethically challenging moments, the healthcare professionals that I worked with drew on a number of skills, which included moral

reflection and moral judgment. This observation prompted me to return to academia to investigate the place and function of conscience in healthcare, an area of research that has now become more timely as the range of end-of-life options in Canada has expanded to include physician-assisted death.

In their survey of conscience-related policies in Canadian healthcare, Jacquelyn Shaw and Jocelyn Downie (2014) found that policies vary greatly across health regions and between different healthcare professions. This prompted them to call for a “meaningful dialogical process”(45) that would best include the voices of all Canadians in the creation of new policies. I agree that such dialogue is necessary. Furthermore, the creation of policies that address conscientious disagreements must be underpinned by a clear understanding of the concept of conscience and its role in the wide variety of relationships found throughout the Canadian healthcare system. If, as I will assert, the consciences of healthcare professionals are an asset for healthcare professionals and those they serve, they must be supported by policies that preserve this critical role in the deliberative processes of healthcare teams.

The background work presented in this dissertation is heavily influenced by the writings of Robert K. Vischer, who addressed the state’s role in fostering conscience and mediating conflicts in a variety of contexts in his book, *Conscience and the Common Good: Reclaiming the Space Between Person and State* (2010). In addition to exploring the history of the concept of conscience, Vischer provided a crucial insight through his notion of the *relational dimension of conscience*. This dimension brings conscience out of the depths of the individual psyche to demonstrate both conscience’s need for relationships and society’s need for conscientious members. For the purposes of this dissertation, conscience is defined as *a judgment about the morality of an act, which must be exercised externally to preserve the integrity of the moral*

*agent*. This definition will be further explicated in Chapter Two in the context of Vischer's writings and related literature.

As policy makers create policies to promote positive resolutions to the full range of situations in which consciences are engaged, they must be attentive to the relationally-oriented consciences of all involved in the healthcare system. In the sections that follow, I will elaborate on cases where conscientious disagreements have escalated into conflicts, as well as on the many situations in which healthcare professionals and their patients have been able to find positive resolutions. Stemming from this contextual overview, I will pose four research questions, explain the significance of my research for future policy in this area, and present the delimitation, limitations, definitions and assumptions for this dissertation.

### **A. Case Studies in Canadian Healthcare**

When healthcare professionals and their patients experience a disagreement that engages their consciences, it can be a challenge for them to reach a positive outcome, wherein both parties feel their conscience rights have been respected. Unfortunately, a number of high profile cases where conscientious disagreements have escalated into conflicts have found their way into the courts, giving the unwarranted impression that irresolvable conflicts are common in the Canadian healthcare system. However, as will be shown in my dissertation, despite the negative image presented by these prominent cases, every day in Canadian hospitals dedicated healthcare teams ably create positive outcomes that respect the consciences of all concerned and bolster the relationship between healthcare professionals and their patients. Given the range of outcomes present throughout the Canadian healthcare system, any discussion of conscience in healthcare must address instances of both negative and positive resolutions to conscientious disagreements.

Negative outcomes may be easier to identify because they often attract national media attention and are described through the legal process. For example, the case of *Cuthbertson v. Rasouli* (2013) exposed many inadequacies in the Canadian healthcare and legal systems' ability to resolve conscientious disagreements. An Ontario man, Hassan Rasouli, went into a coma in 2010 following brain surgery and, to the date of this writing, has remained supported by a ventilator and a feeding tube. Soon after his surgery, Rasouli's doctors, Brian Cuthbertson and Gordon Rubinfeld, expressed their opinion that his condition would only worsen and that he should be removed from life support. However, Parichehr Salasel, Rasouli's wife, who is also a doctor, disagreed with this assessment and sought a court injunction to prevent the doctors from removing her husband's feeding tube and ventilator. Meanwhile, Cuthbertson and Rubinfeld argued that consent from the family was not required for the removal of what they considered to be futile treatment. In 2013, the Supreme Court of Canada ruled that Ontario's Consent and Capacity Board was the legal body that should answer questions regarding consent.

Two years after the Rasouli decision, the Supreme Court of Canada issued a decision in the Carter case (2015) that has changed the landscape of end-of-life decision-making. In this decision, the Court struck down the *Criminal Code* prohibitions on euthanasia and physician-assisted suicide, and they stated, "that a physician's decision to participate in assisted dying is a matter of conscience." The decision goes on to state, "the rights of patients and physicians will need to be reconciled," seemingly leaving this reconciliation in the hands of legislative and regulatory bodies. This decision came into effect on June 6, 2016 and was followed by federal Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, which received royal assent on June 17, 2016 and recognized the freedom of conscience and religion enshrined in the *Canadian Charter of Rights and Freedoms*

(1982). As of this writing, it seems the balance between healthcare professionals' freedom of conscience and patient access has been left in the hands of the Colleges of Physicians and Surgeons and other regulatory bodies in each province and territory.

Although these rulings and the federal legislation provide some insight into how conscientious disagreements will be resolved legally, they do not answer more fundamental questions: Are healthcare professionals required to provide treatment they believe is futile or harmful to their patients? Do patients have a right to access any treatment they desire? Are there ways to resolve disagreements between healthcare professionals and their patients that, unlike the legal system, are non-adversarial?

In seeking the answers to these questions, it is tempting to focus attention on cases where disputes between healthcare professionals and patients have escalated to the level of the courts. However, if we are truly to understand the role conscience plays in our healthcare system, we must also bring our attention to situations in which healthcare professionals and patients have found positive resolutions to their conscientious disagreements. Such cases are examples of *positive deviance* (Pascale, Sternin, and Sternin 2010) and provide valuable insight into ways of fostering positive relationships that respect the consciences of all who are involved in the healthcare system.

American researchers Richard Pascale, Jerry Sternin and Monique Sternin (2010) coined the phrase *positive deviance* to identify the process of looking “for outliers who succeed against all odds” (3). The authors set out their basic premise, stating:

- (1) Solutions to seemingly intractable problems already exist,
- (2) they have been discovered by members of the community itself,
- (3) these innovators (individual positive deviants) have succeeded even though they share the same constraints and barriers as others. (4)

Due to its focus on finding solutions that are already working in a given environment, this method has the advantage of offering practical solutions, rather than imposing top-down policies that may not fit the lived experiences of those concerned. This feature is particularly advantageous in the context of healthcare, which includes a wide range of situations that are unique to the healthcare professionals and patients involved.

In this dissertation, I examine whether palliative care teams may be seen as positive deviants in their efforts to bring resolution of conscientious disagreements. Although research into patient satisfaction in palliative care settings is incomplete (Robinson, Gott, and Ingleton 2014), several studies have found a high degree of patient satisfaction among palliative care patients and families. These studies have portrayed *satisfaction* as including “satisfaction with services, perception of service providers, and likelihood of positive recommendations of services to others” (Brumley et al. 2007, 995). Researchers have used a number of tools for measuring patient satisfaction including the FAMCARE-2 scale (Aoun et al. 2010) and the VOICES questionnaire (Addington-Hall and O’Callaghan 2009), and high degrees of patient satisfaction have been found in a variety of settings including in-home palliative care (Brumley et al. 2007), in-patient hospices (Addington-Hall and O’Callaghan 2009), palliative care day services (Stevens, Martin, and White 2010), and services provided by specialist palliative care teams (Hearn and Higginson 1998). My research will investigate the deliberative processes of the Saskatoon Health Region’s Palliative Care Services, a healthcare team whose FAMCARE results (see Appendix D) show that a strong majority of families surveyed after the death a loved-one were satisfied or very satisfied with the care they received.

The success of palliative care in achieving a high degree of patient satisfaction is noteworthy because palliative care teams are regularly exposed to the ethical challenges found at

the end of life (Schüklenk et al. 2011) from which conscientious disagreements are likely to arise. The success of palliative care is also striking because, while some authors (McLeod 2010) have argued that patients require the full range of legal options to flourish as autonomous individuals, palliative care teams are able to achieve positive outcomes despite limiting the treatment options available to their patients, for example by limiting the number of interventional treatments carried out on patients in their care. The high rate of patient satisfaction in an area of medicine inundated with ethical end-of-life decisions suggests that the deliberative processes of palliative care professionals and teams specially equip palliative care services to achieve positive outcomes to conscientious disagreements.

The purpose of my research was to articulate what deliberative processes, if any, led to the development and maintenance of positive relationships in situations where palliative care team members engaged their consciences within the culture of palliative care. Once articulated, I explored whether these deliberative processes might hold promise to inform the development of a policy framework such as might facilitate the resolution of conscientious disagreements in other parts of the healthcare system.

The following research questions gave guidance to my research proposal:

- (1) What are the experiences of team members who have been directly involved in decisions that engage their consciences within the culture of palliative care?
- (2) How do palliative care providers describe the deliberative processes used at personal, professional and team levels, regarding end-of-life care?
- (3) What part of the deliberative processes described by palliative care team members contributes to the successful mediation of conscientious disagreements between healthcare professionals and patients, as perceived by the healthcare professionals?



- (4) What aspects of palliative care providers' deliberative processes provide insights that inform the development of policy and/or reflections on the practices of professionals in other areas of the healthcare system?

### **B. Significance for Canadian Health Policies Addressing Conscience Issues**

The high patient satisfaction documented in palliative care, an area of healthcare with significant exposure to the ethical challenges found at the end of life from which conscientious disagreements are likely to arise, suggests that the deliberative processes used in palliative care are particularly well-suited to resolving conscientious disagreements. Therefore, the deliberative processes of palliative care have the potential to inform the creation of policies related to conscience issues in other areas of healthcare, especially those that are similarly engaged in end-of-life decision making. Once created, policies that respect the consciences of healthcare professionals and those they serve will foster a *culture of ethical awareness* (Goodpaster 2007, 109), which could lead to several positive outcomes in the healthcare system, including reduced moral distress for healthcare professionals, avoidance of litigation, and improved healthcare professional-patient relationships.

As will be further discussed in Chapter Two, Kenneth E. Goodpaster (2007) proposed that ethically sound organizations are developed and maintained through a “culture of ethical awareness” (109) that respects the consciences of individuals. This culture leads to the development of a corporate conscience that prevents unethical behaviour throughout the organization, as individual members are able to remain conscientiously engaged in their work. In the context of healthcare, conscientiously engaged professionals are valuable not only for the ethics they bring to their organization, but also because the caliber of their work is higher when they are able to avoid moral distress (Huffman and Rittenmeyer 2012, 98).

Moral distress arises when “one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (Andrew Jameton as quoted in Burston and Tuckett 2012). In their literature review of moral distress in nursing, Adam S. Burston and Anthony G. Tuckett (2012) explained that, in morally distressing situations, nurses have reported feeling anger, guilt and exhaustion, which can lead to a range of behaviours from avoiding the patient involved to spending too much time with the patient. Further, the authors stated that, “moral distress has a negative effect on organizational culture” (319) and can lead healthcare professionals to break rules, which “can have a negative effect on broader community relationships” (319). Burston and Tuckett presented several possible remedies for moral distress, including the development of a “supportive culture” (320) that parallels Goodpaster’s culture of ethical awareness, which may be enhanced through a clear policy framework.

I suggest that the development of policies regarding conscience issues may also minimize the risk of litigation against healthcare professionals and their health regions. The Rasouli case is only one instance of a conscientious disagreement finding its way to court; Canadian case law provides several other examples of high profile court cases (Golubchuk v Salvation Army Grace General Hospital et al. 2007; Nancy B. v. Hotel-Dieu de Quebec 1992), many of which have stretched on for months, if not years. Litigation adds to the financial and emotional burdens already experienced by families who have a loved one in critical condition, and strains the financial resources of the hospitals and health regions involved. As the findings of my research have demonstrated, conscientious disagreements can be resolved in positive ways, particularly through the five themes presented in this dissertation: clear communication, collaborative teamwork, a focus on holistic care, the formation of real relationships and engaged consciences.

Policies that support these five areas of the deliberative process of healthcare care professionals are likely to benefit all parties by helping them to avoid the burdens of the legal process.

In addition to the practical burdens of litigation, the adversarial nature of the legal system can erode the relationships between healthcare professionals and those for whom they care. Healthcare professionals and patients both experience high degrees of stress following litigation (Ennis and Vincent 1994), and it may be that the confrontations experienced during the legal process do not remain confined to the courtroom. Although healthcare professionals and patients can and do continue their relationships following court proceedings, these relationships may be better served by a less adversarial process for the resolution of conscientious disagreements. When this negative impact of litigation is coupled with the negative impact of moral distress on the healthcare professional-patient relationship, it is evident that policies that facilitate the positive resolution of conscientious disagreements will enhance the relationships found throughout the healthcare system.

The development of clear policies that foster a “culture of ethical awareness” will benefit patients and their families, healthcare professionals, and healthcare institutions by promoting the skills and tools needed to resolve conscientious disagreements. This allows healthcare professionals and users of the healthcare system to achieve positive outcomes that decrease moral distress, minimize litigation, and reinforce healthy relationships throughout the healthcare system.

### **C. Delimitations, Limitations, Definitions and Assumptions**

This section provides the reader with the delimitations, limitations, definitions and assumptions that undergird this dissertation.

Delimitations:

- This study was delimited to purposefully selected and willing members of the Saskatoon Health Region's palliative care team. It does not include the perspectives of patients or families.
- The data collection phase of this study took place over a period of seven months, from June 2015 to January 2016.
- Data collection was delimited to 12 individual interviews, one focus group and two interpretive panels.
- The literature reviewed in this dissertation was delimited to literature related to conscience theory, relational theory, and conscience in the context of healthcare. Other areas related to this topic, such as organizational development and behaviour, were not reviewed.

#### Limitations:

- This study was limited by the “self-selection” of palliative care professionals whose skills and attitudes may be both similar and different from the general population of healthcare professionals.
- This project was limited by its use of only one palliative care team and their perceptions may not be consistent with those of other palliative care teams in other jurisdictions or contexts.
- My own biases as a researcher will have to some degree impacted on both the data collection and the data analysis. For instance, the questions asked in the semi-structured interviews were limited by my understanding of the literature and experiences in healthcare. These fields of bias were primarily focused on end-of-life care, through my

experiences related to chaplaincy work, and on selected and extant literature related to this dissertation topic.

- Their experiences and perspectives limited interviewees ‘perceptions’ of their own deliberative processes and those of their team.

#### Definitions:

- For the purposes of this study, the concept of *conscience* was defined as a judgment about the morality of an act that must be exercised externally to preserve the integrity of the moral agent. This definition is further explicated in Chapter Two.
  - Although this definition is useful for researchers, it did not resonate with healthcare professionals. Rather than force the language of public policy or philosophy, participants were asked open-ended questions and allowed to frame answers using their own vocabulary.
- A *conscientious disagreement* is understood to be a disagreement in which the consciences of the parties involved are engaged.
- *Deliberative processes* is used in this dissertation to refer to the decision-making activities undertaken by individuals and groups.
- *Healthcare professional* refers to any healthcare worker who is in a position of trust in relation to a user of the healthcare system and belongs to a self-regulating profession. This included but was not limited to physicians, nurses, social workers, physiotherapists, etc.
- *Healthcare team* refers to a group of healthcare professionals who consult with each other while providing care for a patient.

- Although many healthcare professions have chosen to refer to users of the healthcare system as clients, I employed the term *patient* because this nomenclature expresses the power imbalance in the relationship between healthcare professionals and those they serve. This is further explicated in Chapter Two.
- The notion of *positive deviance* challenges researchers to “look for outliers who succeed against all odds” (Pascale, Sternin, and Sternin 2010, 3).

#### Assumptions Used and Reinforced During Course of This Study:

- It was assumed that palliative care was a positive deviant in the context of healthcare. This specialized type of healthcare has succeeded at maintaining respect for the consciences and autonomy of both healthcare professionals and patients, despite being exposed to the ethical challenges at the end of life from which conscientious disagreements are likely to arise. Palliative care teams are thus able to serve as an exemplar for other healthcare teams. The findings of my research suggest that the deliberative processes of palliative care could be adapted for other contexts to improve patient care.
- Following Goodpaster (2007), it was assumed that it would be in the best of interests of institutions to encourage a “culture of ethical awareness” (109) in which the consciences of employees are engaged. The findings of my research support this conclusion and provide insight into how this culture can be maintained.
- Disagreements between patients and healthcare professionals are inevitable, but, as evidenced in the stories shared by the healthcare professionals who participated in my research, most need not escalate into conflicts that require legal intervention.

- In addition to placing emotional and financial strains on the parties involved, it was assumed that litigation harms the healthcare professional-patient relationship and should be avoided whenever possible.

### **Outline of Dissertation**

This dissertation is composed of seven chapters. Following this introductory chapter, in Chapter Two I review selected literature regarding conscience and its role in both the individual and society, with particular attention given to the context of healthcare. In Chapter Three I present the methodology of this dissertation, which used the qualitative method of *narrative inquiry* to investigate the deliberative processes of the Saskatoon Health Region's palliative care team. I present the findings of my research in Chapters Four, Five and Six. In Chapter Seven, I use the analyzed data to respond to the research questions in the context of the literature reviewed in Chapter Two and discuss the implications my findings may have on future policy and research in this field.

## **Chapter Two:**

### **Literature Review**

#### **Introduction**

The previous chapter outlined the purpose of this study, and this chapter consists of a three-section review of selected literature related to the role of conscience in healthcare. First, I define conscience and discuss its role in the life of the moral agent as well as in institutions. Second, I explore the link between conscience and relationships. Third, I provide some insight into factors that distinguish healthcare from other contexts in which conscience concerns arise. While the scope of this chapter does not settle the role of conscience in healthcare, it does clarify a number of key points in the ongoing discussion.

The creation of health policy that addresses the consideration of conscience on the part of healthcare professionals, teams of healthcare professionals and healthcare users is a great challenge because the philosophical underpinnings of conscientious objection and advocacy are still under dispute. Scholars who write about conscience issues in the context of healthcare are typically divided into two groups: those who believe conscientious objectors/advocates harm their patients by their stances and those who believe conscientious objectors/advocates act in the best interests of their patients by their assertions.

In the first group, Carolyn McLeod, a philosopher who leads the *Let Conscience Be Their Guide?* project, espoused a framework that draws heavily on the principle of autonomy. Writing on the subject of emergency contraceptives, McLeod (2010) asserted that women who are denied access to emergency contraceptives are harmed because their “reproductive autonomy, their moral identity, [and/or] their sense of security” is infringed (26). This understanding of conscientious refusal to provide treatment is thought to stem from the belief that healthcare



providers should not be free to exercise their conscience because this could be harmful to their patients.

In contrast, American bioethicist Edmund Pellegrino (2008), who also acknowledged the value of autonomy, believes that healthcare professionals who state their objections (e.g., to emergency contraceptives) will bolster their patients' autonomy by providing them with the input necessary to make informed decisions. "Beneficence, properly exercised," wrote Pellegrino, "is the guarantor of autonomy, rather than its enemy" (214). Therefore, far from being 'yes-persons' whose only function is to meet their patients' demands, healthcare professionals must be free to set limits on the services they provide to ensure their patients are not misled into making poor decisions.

The interpretations of conscientious objection presented by McLeod and Pellegrino are fundamentally different because they disagree about the very nature of the relationship between the healthcare professional and the person receiving care. Whereas McLeod sees a provider who must safeguard the autonomy of his or her<sup>1</sup> clients by supporting all their decisions, Pellegrino sees a professional as one whose willingness to challenge decisions enables her patients to develop their autonomy. These two authors present opposite descriptions of the nature of the conscientious objector's action (i.e., as something that either harms or strengthens patient autonomy).

In an effort to clarify the concept of conscience and its function in human interactions, American researcher Robert K. Visser (2010) distinguished between understanding conscience as a *black box* or as a faculty that is fundamentally relational. The blackbox approach to conscience, which seems to be favoured by McLeod, views conscience as something to be

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<sup>1</sup> Typically, I will use feminine pronouns rather than cumbersome phrases such as "his or her."

exercised independently from outside influences. By contrast, Vischer, along with Pellegrino and others, asserted that by its very nature conscience must be influenced by relationships to function properly.

Vischer called this need for relationships the *relational dimension of conscience*, which he defined as “the notion that the dictates of conscience are defined, articulated and lived out in relationship with others” (3). This understanding of conscience stems from the way conscience is formed, through interaction with the external world, and stipulates that conscience is by definition linked to action. Conscience cannot be locked away from the public sphere. Not only does it require input from others to function properly, it must also be lived out in the real world to preserve the integrity of the individual.

To date, discussions regarding conscience issues in healthcare have been primarily focused on reproductive health; however, conscience issues have a much broader scope of application that covers the range of the human lifespan (Hickson 2011). Decisions that require the efforts of an engaged conscience are especially prevalent at the end of life (Schüklenk et al. 2011), making expressions of conscience more evident in palliative care than in other areas of the healthcare system. However, before the role of conscience in palliative care can be investigated, it is necessary to first define both *conscience* and its *relational dimension*, as well as to provide an introduction to the literature regarding conscience in the healthcare context.

### **A. Conscience in the Individual and in Society**

There may be as many definitions of conscience as there are works written on the subject. However, despite differences in terminology, most authors address the same basic characteristics when trying to express their understanding of conscience. In this section, I will highlight several threads in the conscience-related literature, namely: the component parts of conscience, the

classification of moral reflection, the relationship between conscience and action, and the importance of integrity to both the individual and institutions.

Before delving into this discussion, it will be beneficial to define conscience briefly. Writing in the natural law tradition, Charles E. Curran defined conscience as “the judgment about the morality of an act to be done or omitted or already done or omitted by the person” (2004, 3). As I will show in the following discussion, this relatively simple definition identifies conscience as an act of judgment while providing room for disagreement regarding the mechanisms of this action. Although Curran’s definition is helpful, it neglects conscience’s impact on the moral agent. Therefore, I will modify Curran’s definition to include the relationship between the agent’s conscience and his or her integrity. For the purposes of this dissertation, conscience is *a judgment about the morality of an act, which must be exercised externally to preserve the integrity of the moral agent*. In the following subsections, I will elaborate on several points from the literature to explain my reasons for choosing this definition of conscience.

### **Taxonomy of Conscience**

Although a concept similar to conscience is addressed in both the Hebrew Bible and ancient Greek writings, many modern definitions of conscience are heavily influenced by the natural law philosophy of Thomas Aquinas (2008). Building on the work of early Christian thinkers such as Saint Paul and Saint Jerome, Aquinas distinguished between two parts of “conscience”: *synderesis* and *conscientia*. *Synderesis* was described as a natural habit present in all human beings that incites us to seek good and avoid evil, while *conscientia* applies the knowledge of *synderesis*, i.e., it judges what is good in a particular situation and acts in accordance with that good. For example, *synderesis* alerts most people to the knowledge that

killing another human being is wrong in principle, while the judgment of *conscientia* will help an individual to determine whether or not deadly force is justified in a particular instance of self-defense.

Timothy E. O'Connell (2004) expanded Aquinas' framework in his division of conscience into three parts: conscience/1, conscience/2 and conscience/3. In this schema, conscience/1 roughly corresponds to *synderesis*, but Aquinas' *conscientia* is divided between O'Connell's conscience/2 and conscience/3. Conscience/2 is described as a discernment process that distinguishes good from bad. If the moral agent is to remain true to her commitment to do what is good, the process of conscience/2 necessarily leads to the exercise of conscience/3, which is the event of judging what must be done in a particular situation.

While O'Connell's trifold division included the process of moral reflection (which I consider to be synonymous with terms such as "moral analysis," "discernment," "informing one's conscience" or "moral reasoning"), other authors have excluded moral reflection from conscience (Bebeau, Rest, and Narvaez 1999). For example, Sidney Callahan (1991) stressed that the act of conscience must be focused on a particular event and as such can only include specific acts of judgment. However, she has conceded that "in real life, it often can be difficult to tell where seeking and searching end, and finding and deciding begins" (1991, 21). Whether or not moral reasoning is classified as a part of conscience, it remains the precursor to conscientious judgment and as such needs to be respected and developed if conscience is to function properly.

In many theories, moral reflection draws on different faculties to arrive at a judgment of conscience. Curran asserted that the moral agent "makes decisions in many ways depending on how reason, grace, emotion, and one's intuitions are involved in the judgments of conscience" (2004, 13). This list is echoed in the work of other authors who frequently include one or more of

the following in their understanding of ethical decision making, albeit sometimes they do so under different names: reason (Nussbaum 2011; Aquinas 2008; Birchley 2012), emotion (Downie and Llewellyn 2008; Ouspensky 2008), and intuition (Wilson 1993). Thomas F. Green (1999) provided a considerably different list of faculties, e.g., imagination and memory, which he called the voices of conscience. Green stressed the importance of these different voices:

[D]ilemmas that count are those that arise from the conversation, even the quarrels among the voices of conscience... a developed conscience must be one in which such quarrels continue and are even cultivated, deepened and elaborated. (1999, 29)

Meanwhile, although Callahan did not consider moral reasoning to be part of conscience, she stated that conscience integrates “reason, emotion and will” (1991, 14). For the purposes of this dissertation, moral reasoning will be understood to be a precursor to conscience and that, at a minimum, conscience arrives at a judgment through the interplay of reason, emotion, and intuition.

Consider, for example, the case of a woman who is trying to decide whether or not her husband’s ventilator support should be discontinued. Her reason may help her to consider the doctor’s advice that the ventilator support should be discontinued because it is only prolonging her husband’s inevitable death. Meanwhile, the woman’s emotions may tell her that consenting to the removal of the ventilator will make her complicit in her husband’s death. Finally, her intuition may reveal that it is time to say goodbye to her spouse. All of these voices will be mediated by conscience, which will make the final judgment regarding the course of action that is in keeping with the woman’s conception of the good.

When judging a possible course of action, the conscience does not tell the actor what she *could* do or what she would *like* to do, but rather what she *must* do. This distinguishes conscience

claims from preferences because “the person judging makes a statement about the object of her judgment, not just about her interior disposition” (Vischer 2010, 81). Vischer explained:

If I prefer chocolate ice cream to vanilla, I am not opining that chocolate is better than vanilla. As Emile Durkheim puts it, such judgments “do not attach value to objects but merely affirm the state of the subject.” If, however, I ask for chocolate ice cream as a matter of conscience, I am stating, at a minimum, that eating chocolate ice cream is morally superior to eating vanilla. (p. 76)

Vischer asserted that conscience is distinct from preference because conscience carries the authority of a truth claim that takes the actor beyond her own emotions or desires to a judgment of what is actually true. Viewing conscience as a truth claim does not mean that conscience is free from error. As is the case with all human judgments, conscience remains susceptible to human limitations (Curran 2004; Callahan 1991). However, the possibility of error diminishes neither the agent’s commitment to do the good nor her belief that a certain action is good and therefore must be carried out. Unlike preferences, the judgments of conscience must be followed if the actor is to maintain her integrity, a point to which I will return in the next subsection.

Although most scholars who write directly about conscience agree that conscience is a judgment that goes beyond mere preferences (Sulmasy 2008; Callahan 1991; Carter 1997), the tendency to devalue the judgments of conscience remains in many works addressing conscientious refusal in healthcare. For example, prominent bioethicist Julian Savulescu (2006) wrote that, “conscience, indeed, can be an excuse for vice or invoked to avoid doing one’s duty” (p. 294). In an oft quoted passage, he has also stated: “The door to ‘value-driven medicine’ is a door to a Pandora’s box of idiosyncratic, bigoted, discriminatory medicine” (p. 332). While Savulescu represented an extreme position, efforts to balance conscience in healthcare relationships remain divided, which will be addressed in subsequent sections.

In contrast to Savulescu's dismissal of conscience, other authors have attempted to clarify the distinction between conscience and personal whim. One proposed method of distinguishing the judgments of conscience from preferences is to evaluate the nature of the claim being made. Sidney Callahan (1991) explained that, "the inner, self-assessing dialogue [of conscience] can be engaged in, not only to work things out for ourselves, but also to prepare us to morally justify to others what, why, and how we are deciding" (p. 20). While preferences simply exist as a subjective opinion, the claims of conscience carry much more weight because they can be justified (Vischer 2010; Wilson 1993; Birchley 2012).

The above discussion of conscience leads to several possible conclusions. First, a commitment to conscience entails a commitment to do what is good while conscience itself is a judgment about whether or not a particular action is good. Second, the process of discerning what is good (i.e., moral reflection) will be distinguished from conscience here, but remains valuable even if it is included as a component of conscience. Third, the judgments of conscience are distinct from preferences because they can be justified and must be followed to preserve the agent's integrity, a point to which I will now turn.

### **Why is Integrity Important to the Individual?**

I have identified two ways in which the judgments of conscience differ from preferences. First, the judgments of conscience must be followed to preserve the integrity of the agent, whereas failure to act on preferences has no impact on integrity. Second, the judgments of conscience can be justified whereas preferences cannot. In this section I will explore the concept of integrity, which is tied to justification, and explain the role integrity plays in the wellbeing of the individual.

In his survey of conscience, Sulmasy (2008) addressed the connection between conscience and integrity. Sulmasy described conscience as being “rooted in a fundamental commitment” (p. 138) to act in accordance with the good. The judgments of conscience are therefore judgments about whether or not a particular act would violate this commitment, and persons of integrity are those who uphold their commitment to act in accordance with the good as “the most fundamental of all moral duties” (p. 138). Although Sulmasy did not detail the effects of a breach of integrity, he did state his view that a lack of integrity diminishes our humanity.

A similar but more comprehensive account of integrity can be found in Stephen L. Carter’s appropriately titled book, *Integrity* (1997). Carter divided integrity into three steps:

- (1) discerning what is right and what is wrong;
- (2) acting on what you have discerned, even at personal cost; and
- (3) saying openly that you are acting on your understanding of right from wrong. (p. 7)

The first step clearly corresponds to the concept of moral reflection discussed above. However, in his discussion regarding the first step Carter did not identify moral reflection as a precursor to conscience, but rather understood conscience as something that informs discernment. Despite this different articulation of the relationship between conscience and moral reasoning, Carter continued to emphasize conscience’s role in providing the agent with the knowledge of right and wrong. This leads to the second step of integrity, which confirms moral judgment as a precursor to action. It is here that we find not only that the agent knows what is right, but also that she *must* do what is right if she is to maintain her integrity. Carter’s third step forms another connection with the concept of conscience developed above by emphasizing the importance of justifying one’s actions. In addition to distinguishing acts of conscience from preferences, the ability to justify one’s judgments also ensures the agent is acting in a morally integrated manner. Persons



of integrity are therefore persons who take the time to discern right from wrong, act in accordance with what is right, and are willing and able to justify their actions even in the face of scrutiny.

Carter's three steps provide a clearer understanding of what integrity is and why conscience is so fundamental to an integral life, but they do not explain why integrity is indispensable to the individual. For this answer, we turn again to Vischer who built on the work of David Hume, Albert Camus and Charles Taylor to defend the individual's need for a coherent life narrative (i.e., an integral life). A coherent life narrative provides the agent with a foundation upon which to discover her personal identity, which further enables her to form relationships with others. Disruptions to this narrative, such as those caused by acting against one's commitment to do the good, initiate a ripple effect that negatively impacts the agent's self-identity, and by extension her relationships with others. Vischer explained that, "the exercise of conscience is not just an expression of a person's identity; it is a means by which a person's moral identity may become fully and coherently formed [...] More fundamental [than self-expression] is the value we place on one's ability to live life as a narrative" (2010, 71).

The importance of conscience for individual fulfillment is also reflected in Martha Nussbaum's (2011) articulation of the Human Development Approach. Nussbaum listed ten core capabilities that must be fostered in every person to help her reach her full potential. The capability of practical reason, which is defined as "being able to form a conception of the good and to engage in critical reflection about the planning of one's life" includes "protection for the liberty of conscience and religious observance" (p. 34). Practical reason is also identified as an architectonic capability that is necessary to ensure all other capabilities are developed in a way that will maximize the individual's freedom. "Good policy in the area of each of the capabilities

is policy that respects an individual's practical reason;" wrote Nussbaum, "this is just another way of alluding to the centrality of choice in the whole notion of capability as freedom" (p. 39). Nussbaum, along with other proponents of the Human Development Approach (Sen 1999), recognized that the freedom to act on one's own conception of the good is of fundamental importance to the wellbeing of the individual.

Although most authors agree that integrity is essential to personal wellbeing, they disagree on the weight freedom of conscience should be given when it is balanced with other goods. While this is an important discussion, it is beyond the scope of this dissertation. I will turn instead to explore the value that persons of integrity bring to society.

### **Why is Integrity Important to Society?**

From the discussion above, it is clear that integrity is crucial for the wellbeing of the individual. It is a fundamental freedom, and is enshrined as such in the *Canadian Charter of Rights and Freedoms* (1982) through section 2a, freedom of conscience and religion. Beyond the personal benefit to individuals, respect for integrity is also indispensable to society as a whole. Integrity is not an obstacle that successful societies must overcome; rather, it is widely considered to contribute to the flourishing of both communities and institutions. For the purposes of this dissertation, "institution" refers broadly to both organizations and "the humanly devised constraints that shape human conduct" (North 1990, 3). Examples of institutions in the context of healthcare are diverse, including professional codes of conduct, professional organizations, hospitals, health regions and the Ministry of Health.

In her work evaluating the role of conscience in law abiding citizens, Lynn Stout (2010) provided a simple definition of conscience as "an internal force that inspires unselfish, prosocial behavior" (6–7). Reacting to the American legal tradition's tendency to treat citizens as *homo*

*economicus*, the self-interested man of traditional economics, Stout focused instead on the value of the conscientious behavior witnessed in most citizens. Stout cautioned against assuming that the heavy hand of the law is the only thing that keeps citizens in line, arguing that the most useful laws incentivize people to act in an unselfish, prosocial manner. “[I]n our quest for a peaceful and prosperous society,” wrote Stout, “we may put rules to work best when we put them to work in tandem with conscience” (237). Incentives provided through laws and regulations that reinforce conscience are the most effective way to encourage good citizenship.

Stout’s analysis of conscience and law parallels Nussbaum’s articulation of the Human Development Approach. Nussbaum’s capabilities, including practical reasoning, are necessary not only for the flourishing of the individual, but also for the flourishing of communities and nations. Proponents of the Human Development Approach assess a nation’s success by reference to personal capabilities not only because these capabilities are an indication of personal freedom, but also because they contribute to the development of the nation as a whole. As Amartya Sen (1999) pointed out, “the achievement of [national] development is thoroughly dependent on the free agency of people” (4). A flourishing society is one in which people are free to contribute to their communities in keeping with their understanding of the good.

The value of conscience and integrity is also evident at the institutional level, as evidenced by Kenneth E. Goodpaster. After analyzing corporate disasters such as the Enron scandal, Goodpaster identified a pathology as a root cause. This pathology, which he referred to as *teleopathy* (from *telos* meaning *end*, and *-pathy* meaning *disorder*), is present in many types of organizations and follows a three-step pattern: fixation, rationalization, and detachment. The term *teleopathy* is derived from the first step in which an organizational culture becomes fixated on a specific goal, such as economic profit. In the following step, the group rationalizes its

behaviour, convincing participants that the end goal is worth sacrificing other goals and principles. The rationalization process is repeated until finally, in the third step, the consciences of individual members are numbed, and become detached from the organizational culture. This separation of everyday morality from the business world paves the way for unethical behaviour throughout the organization.

According to Goodpaster, the antidote to teleopathy is corporate conscience. Goodpaster defined conscience as, “an active, engaged, perspective on decision-making that realizes the significance of others” (2007, 62) and highlighted the conscientious person’s respect for the goals of others. In contrast to Stout’s focus on conscience as motivating unselfish behaviour, Goodpaster stressed that conscience challenges the actor to bring her goals into alignment with the goals of others, effectively reinforcing self-interested actions that are beneficial to all. When this understanding of conscience is developed in corporations, leaders value the rights and goals of all stakeholders and break free of their teleopathy. At both the personal and the corporate level, Goodpaster defended conscience as a more effective method for preventing unethical behaviour than external legal or economic sanctions (2007, 5).

Corporate conscience, which Goodpaster presented as an amalgamation of the consciences of individual group members, may be fostered through the development of a *culture of ethical awareness* (2007, 109). Goodpaster proposed that managers provide the key linkage in the development of corporate conscience because they can ensure both that individuals understand the organization’s shared values, and that the corporation provides individuals the space they need to voice their concerns. Providing leadership of this nature requires flexibility and patience to avoid the extremes of either dictatorship or relativism, but Goodpaster believed such leadership is possible if respect for others remains the core value. “The company that values

respect *for* others,” wrote Goodpaster, “will be more likely to respect the values *of* others” (2007, 214).

The works of Stout, Nussbaum and Goodpaster show that the freedom to follow the judgments of one’s conscience (i.e., integrity) is considered essential for the wellbeing of the individual, the communities and the institutions of which one is a part. When approaching conscience issues, policy makers must keep the wellbeing of individuals at the forefront. The definition of conscience, presented at the beginning of Section A, emphasized conscience’s fundamental role in preserving integrity: Conscience is a judgment about the morality of an act, which must be exercised externally to preserve the integrity of the moral agent. This definition is resonant with the findings of my research, which provide further evidence of the linkages amongst moral reflection, conscience, action and integrity.

## **B. The Relational Dimension of Conscience**

The discussion of conscience in Section A was primarily focused on conscience’s inner workings. However, to fully understand conscience the discussion must move beyond this interior dimension to explore conscience’s interactions with the external world. Vischer referred to this external orientation as the *relational dimension of conscience* and stressed its fundamental role in both the development and the living out of conscience, a role that is supported by the findings of this dissertation. This section will introduce Vischer’s concept of the relational dimension of conscience, address its compatibility with the relational theory that is prominent in feminist health law and policy research, and explore the concept of power as it pertains to relationships.

At the beginning of his discussion of conscience, Vischer cautioned against treating conscience as a *black box*. The black box approach to conscience views conscience as self-

contained and disconnected from outside influence. The judgments of this conscience cannot be justified, and can therefore only be either respected or ignored by actors outside the individual. Although the black box conscience does appeal to some authors (Savulescu 2006), Vischer warned that, “a strictly individualized conception of conscience will obfuscate the need for society to defend the myriad relationships that are integral to conscience’s full flourishing” (2010, 15). Far from being a black box, by its very nature conscience must be open to relationships to function properly.

Vischer defined the relational dimension of conscience as “the notion that the dictates of conscience are defined, articulated and lived out in relationship with others” (2010, 3) and accentuated the point that conscience must be exercised externally, as noted in the definition of conscience in Section A. Vischer’s account of conscience was rooted in two claims: first, that conscience is formed through relationships; and second, that the judgments of conscience can be justified through dialogue with others. Both claims emphasized the external orientation of conscience and link the judgments of conscience to action. In short and accordingly, a fully functioning conscience must be lived out in the world where it can be enriched by and enrich the consciences of others.

Vischer’s first claim, that the formation of conscience is embedded in relationships (2010, 78), finds support by most authors in the field of moral education. Maintaining the importance of others in one’s personal life narrative, Callahan stated:

Individuals shape their own characters and create their moral careers by large and small moral decisions. We interpret our social worlds and select our own environments, as well as the other way around. Yet at the same time, no individual is self-created *de novo*, nor can anyone live a moral life alone. The self is always partially constituted by a history of interpersonal relationships within a specific community and culture. (1991, 199)

Similarly, Wilson wrote that conscience arises “out of our innate desire for attachment” and is, therefore, strongest when it is formed in relationship with others (1993, 105). Meanwhile, Green addressed the importance of forming one’s conscience in public to ensure both that the individual’s conscience benefits from the experience of others, and that the individual is able to make meaningful contributions to public life (Green 1999). Although the mechanisms for formation of conscience vary, the consensus is clear: conscience is formed in relationship with others.

Vischer’s second claim, that persons outside the individual can engage conscience, was discussed in section A. However, it is worth noting that the relational dimension of conscience reinforces conscience’s connection to action. Not only is following the dictates of one’s conscience necessary to preserve one’s integrity, it is also necessary to ensure conscience maintains its external orientation. “Conscience, by its very nature, directs our gaze outward, to sources of formation, to communities of discernment, and to venues for expression,” wrote Vischer. He continued, “when the state closes down avenues by which persons live out their core beliefs [...] there is a cost to the continued vitality of conscience” (2010, 4). Vischer asserts that conscience cannot function if it is detached from the real world actions that are necessary for the creation of authentic relationships, a claim that is supported by the findings of my research that evidence the connection between conscience and the web of relationships found throughout the healthcare system.

In addition to enriching the definition of conscience already provided, Vischer’s relational dimension of conscience is also compatible with the relational theory espoused by Canadian health law and policy writers such as Jocelyn Downie and Jennifer Llewellyn (2008). In contrast to liberal theories that view the individual as isolated, relational theory is rooted in the

concept of the *relational self*, which Downie and Llewellyn described as “socially connected, interdependent, socially encumbered, emotional, relationally constructed, socially constituted, and embodied” (p. 196). The relational self parallels the relational dimension of conscience as both are influenced by a host of positive and negative relationships through which the moral agent finds her own identity.

Downie and Llewellyn’s relational self is further illuminated through their account of autonomy. While liberal theories have traditionally understood autonomy to correspond to the independent self-governing of the individual (Christman 2011), relational theories take a different route. Downie and Llewellyn (2008) defined autonomy as:

the capacity for defining, questioning, revising, pursuing one’s interests and goals that is exercised, protected, and corroded within relationships and social structures which together shape the individual and determine others’ responses to her. (198)

Like Vischer’s conscience, relational autonomy is not atomistic and cannot be exercised free from the influence of others. Rather, this autonomy is the product of a web of relationships that can limit or strengthen the actor’s ability to exercise her will.

Although Downie and Llewellyn did not connect their work with Vischer’s, both placed a heavy emphasis on the relationships in which the moral agent is enmeshed. However, whereas Vischer did not provide much insight into the kinds of relationships that affect the individual, Downie and Llewellyn supplied a nomenclature for the different forces that influence autonomy. They label these forces as either external or internal, and further divide each category into direct or indirect. External direct forces are perhaps the easiest to witness (e.g., the threat of violence), while external indirect forces typically limit a person’s options in a more covert manner (e.g., when a treatment is so expensive that it is no longer an option). Meanwhile, internal forces come from within the individual and can be either direct (e.g., when a person’s obsession with physical



beauty influences her decisions regarding cosmetic surgery), or indirect (e.g., when a person's history as a victim of violence immobilizes her). The health policy scholars explained that these forces "must be attended to and resisted where restrictive or corrosive and promoted where enhancing" (2008, 203).

In their admittedly brief treatment of autonomy, Downie and Llewellyn did not provide a method for distinguishing between positive enhancing forces and negative corrosive forces. Fortunately, however, the forces discussed by Downie and Llewellyn parallel Steven Lukes' three dimensions of power, which can provide some insight. In his book, *Power: A Radical View* (2005), Lukes distinguished between overt, covert and latent power. A rough comparison reveals that Downie and Llewellyn's external direct forces correspond to instances of overt power, whereas indirect forces correspond to instances of Lukes' covert power that limits the options available to the agent. The third dimension of power identified by Lukes is latent power, described as any instance in which there is "a contradiction between the interests of those exercising power and the real interests of those they exclude" (p. 28). This latent power often goes undetected, but could be present throughout the forces presented by Downie and Llewellyn.

Lukes' work is particularly valuable because it provides a key distinction between influence and power that can be used to separate Downie and Llewellyn's enhancing forces from their corrosive forces. Lukes defined power in the following way: "*A* exercises power over *B* when *A* affects *B* in a manner contrary to *B*'s interests" (2005, 37). For Lukes, power is only present when there is a conflict between the interests of two individuals, a clear analogue to Downie and Llewellyn's corrosive forces. Further, Lukes' would classify enhancing forces as instances of influence that are outside the scope of power. To clarify his position, Lukes

presented a test for determining whether or not the relationship between two persons is an instance of power, writing:

We can now turn to the analysis of what exactly is involved in identifying an exercise of power... in brief, we need to justify our expectation that *B* would have thought or acted differently; and we also need to specify the means or mechanism by which *A* has prevented, or else acted (or abstained from acting) in a manner sufficient to prevent, *B* from doing so. (2005, 44)

While this test does not prove the existence of the widespread and pervasive power found in some theories (Foucault 1991), it does indicate that power can be found throughout relationships in all areas of human interaction. For relational autonomy to flourish, policies must consider the different forces at play in a person's life, reinforcing positive influences while dissipating negative relationships that exercise power (Downie and Llewellyn 2008, 204).

Turning again to the relational dimension of conscience, although Vischer did not dwell on the different types of relationships present in society, he did state that conscience is exposed to a multitude of positive and negative forces in what he terms the *moral marketplace* (2010, 4–6). In his discussion of the role of the state in this moral marketplace, Vischer left room for policies that interfere with the marketplace as long as they expand “social participation and [mitigate] or [prevent] the identity squelching harms of certain relationships” (121). However, he maintained that the goal of the state should be to support the moral marketplace with minimal interference, allowing relationships between individuals to develop naturally. The security of the moral marketplace is vital because it is here that the conscience is both developed and expressed.

Vischer's relational dimension of conscience revealed conscience's essential connection to the external world, both in its formation and its expression. This focus on relationships is echoed in the relational theory of Canadian health law and policy scholars, who similarly emphasize that the moral agent is enmeshed in a web of relationships. These relationships can be

positive instances of influence or negative instances of power, and should be taken into consideration when developing policies regarding conscience issues, because, as my research demonstrated, relationships and conscience are interdependent. In the following section, I explore some of the questions that need to be addressed when developing such policies in a healthcare setting.

### **C. The Healthcare Context**

As explored in the previous two sections, the external expression of conscience is deemed critical to the flourishing of both the individual and the institutions to which she belongs. In a healthcare environment, both individuals and institutions are exposed to a diverse range of ethical challenges that impact the development and expression of conscience (Juthberg and Sundin 2010). These challenges are unique due to the hierarchical nature of relationships throughout healthcare institutions and the high importance of ensuring access to medical care (Birchley 2012). As an introduction to the context of healthcare, this section will explore two key questions:

- (1) How does the concept of power inform our understanding of the healthcare professional-patient relationship?
- (2) How do the consciences of healthcare professionals and users of the healthcare system impact healthcare institutions?

#### **Power in the Healthcare Professional-Patient Relationship**

The discussion of power in Section B established that power is found in a diverse range of human interactions. The healthcare context presents a variety of relationships between members of the same profession, members of different professions, and between healthcare professionals and users of the healthcare system. This section focuses on the latter set of

relationships. Although many healthcare professions have chosen to refer to users of the healthcare system as clients, as previously indicated I employ the term “patient” because it expresses the imbalance in the relationship between healthcare professionals and those they serve. Healthcare professionals have a great potential to influence their patients because they have wider access to information and can control the options available to those in their care. In the following discussion, I will explore this imbalance using Lukes’ framework for power.

As noted above, Lukes identified the exercise of power as an instance in which “*A* affects *B* in a manner contrary to *B*’s interests” (2005, 37). When applied to the context of healthcare, it is evident that there is great potential for a healthcare professional to exercise power over her patient. However, it must be stressed that even with this potential, a relationship can only be identified as an instance of power if the healthcare professional acts against her patient’s interests. This can be distinguished from French and Raven’s (Raven 2008) framework for the bases of power, which are present if *A* has the potential to influence *B* whether this influence is positive or negative. Lukes’ framework leads to several different ways the potential for power could be expressed in a healthcare relationship based on, first, whether or not both parties agree on what constitutes the patient’s interests, and, second, the action taken by the healthcare professional. I will look at each case in turn.

In the first set of cases, where the healthcare professional and the patient are in agreement regarding the patient’s interests, the healthcare professional can either act in accordance with those interests or against them. If the healthcare professional acts in a manner that reinforces the patient’s interests, their collaboration is an instance of influence, not of power. For example, a patient may be diagnosed with diabetes and agree to follow the guidance of her nurse in learning how to test her blood sugar level. In a second instance, power is clearly expressed if the two

parties continue to agree on the interests of the patient but the healthcare professional acts contrary to those interests. For example, a pharmacist who is asked to fill a prescription for strong pain relievers could know these drugs are needed by the patient but still choose to give the patient a water pill and sell the pain relievers on the black market for her own personal gain.

The second set of cases, in which the two parties disagree about the interests of the patient, are considerably more difficult to classify. Disagreements about the interests of the patient seem to be inevitable in healthcare, and can occur between healthcare professionals themselves as well as between professionals and patients. In his 1975 article, “Regarding the End of Medicine and the Pursuit of Health,” Leon Kass argued that, although everyone values healthcare, there is no universal understanding of “health” or what the goal of healthcare should be. Kass dismissed false goals such as happiness, beauty, and the prolongation of life, focusing instead on health as “the well-working of the organism as a whole” (1975, 29). However, not every person will agree to this goal, and, even among those who do, there remains disagreement about what actions lead to wholeness. Since Kass’ article was written, the scope of medicine has continued to expand with major advancements in, for example, cosmetic surgery, reproductive technologies, and life prolongation. If consensus on the goal of medicine was uncertain in 1975, it is even more elusive today. As noted by Michael W. Hickson, the goal of medicine is worthy of more reflection (2011, 15), but it will not be further addressed here.

When a healthcare professional and a patient cannot agree on the goal of healthcare, it is likely they will be unable to agree on the interests of the patient as well. In cases where a healthcare professional and her patient cannot agree on a treatment plan, there are three options available to the healthcare professional: (1) she can treat the patient in keeping with the professional’s understanding of the patient’s interests; (2) she can treat the patient in keeping

with the patient's understanding of her own interests; or (3) she can provide no treatment. The first option could only be carried out through an exercise of power over the patient, and although Lukes' believes this is acceptable if there is proof that the patient's understanding of her own interests is flawed (2005, 37), Canadian health law does not support this conclusion. In Canada, patients have the right to refuse treatment except in cases where the patient lacks the capacity to make decisions and no substitute decision maker is present (Schüklenk et al. 2011). For example, capable adults may decline blood transfusions even if this refusal will lead to death. Although there are other factors in play in such cases, further discussion is beyond the scope of this dissertation.

Although real life situations are seldom clear-cut, in general this leaves only the second and third options legally open to the healthcare professional: she can either provide treatment she does not believe is in the interests of her patient, or she can provide no treatment. The healthcare professional's decision will engage her conscience as she considers whether or not she can maintain her integrity (i.e., her commitment to do good), while either performing the action requested of her or refusing to provide treatment. In such a deliberation she will have to consider many factors, but I will focus here briefly on how the healthcare professional's understanding of autonomy may influence her decision.

In their discussion of relational autonomy, Downie and Llewellyn asserted that health law and policy should foster autonomy-enhancing relationships and resist autonomy-corroding relationships. However, while their account justified the moral agent's need for freedom from the power of corrosive relationships, it is unclear what action a healthcare professional should take when there is a disagreement over the patient's interests. If the enhancement of autonomy is always assumed to be in the patient's interests, the key question becomes: Will the patient's

autonomy be more enhance by (a) a healthcare professional who carries out an action she believes will harm the patient; or (b) a healthcare professional who expresses her concerns and refuses to provide treatment?

Answers to this question are divided, revealing stark differences in scholarly opinion between those defending option (a) and those defending option (b). Authors who support option (a) often do so out of a commitment to ensure that healthcare providers cannot exercise power over their patients in any form. For example, writing in the context of pharmacists refusing to provide emergency contraception, Carolyn McLeod (2010) argued that, “conscientious refusals threaten women’s reproductive autonomy if they accentuate the stigma associated with [emergency contraception] so much that out of shame or embarrassment, women stop trying to obtain it” (p. 19). In such cases, the healthcare professional’s refusal is corrosive to her patient’s autonomy, and, according to McLeod, the healthcare professional should therefore subvert her own conscience in the interest of maintaining her patient’s autonomy.

However, there are opponents to this view of a fragile autonomy. Self-determination theorists Ryan and Deci (Ryan and Deci 2006) stressed the value of autonomy, but asserted that, “independence is not a universal need; having many options is not a basic need, nor is it even always edifying” (1580). In a similar vein, Holly Fernandez Lynch wrote that, “One is not harmed by the bare fact of having another person disagree with him or her” (2008, 151), going on to state that disagreements are unavoidable in a pluralistic society. Similarly, although Edmund Pellegrino (2008) focused most of his discussion regarding conscience concerns on balancing the patient’s right to autonomy against the healthcare professional’s right to maintain her integrity, he also provided a discussion of autonomy that is aligned with relational autonomy. He wrote:

It is a distortion of the idea of autonomy to equate it with total independence from the physician or others in making treatment decisions... Human beings live in community and personal association especially when they are patients. Patients especially need the input of others if their own choices are to be genuine ones. Physicians are needed to provide information and to discuss this information with patients to enable and empower them to use their autonomy wisely. (207–208)

Working against the perception that the principles of autonomy and beneficence are in conflict, Pellegrino went on to state: “[b]eneficence, properly exercised, is the guarantor of autonomy, rather than its enemy” (214). Far from being yes-men who perform any action requested of them, beneficent healthcare professionals must engage their patients and express their concerns. According to Pellegrino, failure to do so will actually be detrimental to their patients’ autonomy because it will rob them of the opportunity to be enriched by others. Put another way, healthcare professionals who do not engage their patients regarding matters of conscience prevent them from participating in Vischer’s moral marketplace (2010).

In addition to supporting relational autonomy, many authors also believe conscience plays a positive role in the provision of care. Although Donald A. Schon did not refer to conscience explicitly in his book, *The Reflective Practitioner* (1984), he identified professionals as people who reflect-in-action, making adjustments and learning as they engage in their work. In regard to the professional’s moral reasoning, Schon stated:

When [the professional] is confronted with demands that seem incompatible or inconsistent, he may respond by reflecting on the appreciations which he and others have brought to the situations. Conscious of a dilemma, he may attribute it to the way in which he has set his problem, or even to the way in which he has framed his role. He may then find a way of integrating, or choosing among, the values at stake in the situations. (63)

Schon’s understanding of the importance of moral reasoning in professional decision-making was furthered by Birchley (2012), who wrote that, “in the sometimes fast-paced decision-making of healthcare, [conscience’s] ability to grab the moral attention may give it an important advantage over more deliberative mechanisms” (16). Anika Jensen and Evy Lidell’s (2009)



qualitative study into the effects of conscience in nursing also indicated that conscience has a positive impact. They reported that nurses value their conscience because it promotes a sense of duty, helps them to be aware of inadequate care, and increases their level of sensitivity towards their patients. This is by no means a complete survey of the literature on the effects of conscience on patient care, but it does indicate that conscientious healthcare professionals are beneficial for patients. This assertion is further supported by the findings of this dissertation, as the healthcare professionals interviewed explicitly and implicitly indicated that their conscience was an asset in their work.

The focus on patient autonomy found here is not meant to exclude conversations regarding balancing the rights of patients with the rights of healthcare professionals, such as those found in Lustig (2012); McLeod (2010); Pellegrino (2008); and Rutland (2009). When discussing the healthcare professional's side of the scale, it is necessary to establish whether or not her claim to personal integrity can be swept away by her chosen vocation (Lynch 2008, 196–207). On this point, I echo Nussbaum's assertion that the "goal is not to use some people as a means to the capabilities of others or of the whole" (2011, 35). Rather, our society will flourish when the integrity of all is respected. As noted earlier, this conversation is worth exploring, but it is beyond the scope of this dissertation.

### **The Value of Conscience in Healthcare Institutions**

In addition to its positive impact on individuals, respect for conscience also benefits institutions. This is particularly evident in healthcare institutions, which have become the locus of our society's most important ethical discussions concerning life and death (Somerville 2004). Like all institutions, healthcare institutions rely on the consciences of their members to ensure

they behave morally. In this section I will explore this dynamic by applying Goodpaster's corporate conscience to the Canadian healthcare context.

The notion that institutions have consciences is not unique to Goodpaster (Sulmasy 2008; Pellegrino 2008, 293); however, his analysis of corporate America provides insight into what can happen when conscience is suppressed in any institution. As outlined in Section A above, Goodpaster observed a three step pattern that leads to institutional disasters: fixation, rationalization, and detachment. I propose that the Canadian healthcare system and the organizations within it are as susceptible to these steps as any other institution. Healthcare institutions can become fixated on certain goals, for example lowering wait times or minimizing length-of-stay; they can rationalize this fixation by repeatedly justifying the supremacy of their chosen goal over other values, such as ensuring ethical treatment of patients or following labour standards; and finally, this can lead both employees and users of the healthcare system to numb their consciences, detaching their moral selves from the healthcare environment. As Goodpaster noted, this paves the way for an institutional culture that is no longer ethically aware.

Canadian healthcare institutions are particularly susceptible to the decay of organizational culture that suppression of conscience brings because, as Albert Hirschman would say, Canadians cannot exit the healthcare system. In his book, *Exit, Voice and Loyalty* (1970), Hirschman explained that most institutions rely on cues from members or customers to signal the need for change. These cues come in the form of either exit (i.e., members and customers leave the organization), or voice (i.e., members and customers express their desire for change). While these two options are viable in many organizations, the healthcare context differs because most healthcare professionals and patients are not able to leave the Canadian healthcare system. This

leaves voice as the only mechanism available to signal the need for change to the rest of the institution.

The Canadian healthcare system's reliance on voice makes freedom of conscience all the more important in this context. Hirschman (1970) wrote that, "While exit requires nothing but a clear-cut either/or decision, voice is essentially an *art* constantly evolving in new directions" (43). Organizations must encourage the voice option because individuals will only voice their concerns if there is a low opportunity cost in doing so (38–39). If Canadian healthcare is to avoid decline, it must continue to provide both healthcare professionals and patients the opportunity to exercise their consciences in a meaningful way that carries minimal repercussions for those who voice their concerns. This may have the added affect of fostering loyalty to healthcare organizations, which Hirschman described as a quality that "holds exit at bay and activates voice" (78). Although few healthcare professionals can exit the Canadian healthcare system physically, there may remain a danger that they could withdraw their commitment to the system, becoming demoralized and merely performing their duties adequately, rather than with a commitment to excellence.

The literature on healthcare institutions reveals several possible approaches to conscience issues that can only be mentioned in passing here. As they work to reinforce respect for others, healthcare institutions could commit themselves to fostering organizational conscience by using management to ensure that individuals are both aware of the organization's values and are able to contribute to the organizational culture, as proposed by Goodpaster. Alternatively, in her book, *Conflicts of Conscience in Healthcare: An Institutional Compromise* (2008), Lynch provided a more concrete solution, suggesting that licensing boards should bear the responsibility of ensuring there are enough healthcare professionals to provide access to

controversial services. However, although Lynch's solution protects conscientious objectors, it would be challenging if not impossible to implement in sparsely populated regions of Canada. Another option is given by Birchley, who suggested that examination boards could be used to judge the authenticity of conscientious objection, although he admits that this does not solve the problem of patient access (2012, 15). Any policy that is put into practice must be tailored to the specific challenges of the Canadian healthcare landscape.

This section has only provided a snapshot of Canadian healthcare and the concerns found therein. However, it is evident that this context brings unique challenges due to the distinct relationships found within the healthcare environment and the nature of Canadian healthcare institutions. Despite these challenges, much of the literature reflects the importance of maintaining an environment in which conscience remains active to guarantee both the flourishing of individuals and the continuing prosperity of institutions.

### **Summary**

This chapter has explored major threads in the literature regarding conscience and conscientious objection to treatment in healthcare. Conscience has been defined for the purposes of my research as a judgment about the morality of an act, which must be exercised externally to preserve the integrity of the moral agent. The judgments of conscience have been distinguished from preferences to highlight the indispensability of conscience in the moral agent's formation of a coherent life narrative. Special attention has been given to Robert K. Vischer's relational dimension of conscience and the role of relationships in the formation and exercise of conscience, particularly in regards to the healthcare professional-patient relationship. The concept of corporate conscience has also been developed and applied to the Canadian healthcare context. As will be discussed in further chapters, the literature reviewed here provides the

context needed to explore expressions of conscience in palliative care and will be needed to answer the research questions posed by my research. The following chapter will address the methodology and methods used in this dissertation.

## **Chapter Three:**

### **Methodology, Methods and Analysis**

#### **Introduction**

The previous two chapters explored the purpose of this study and selected literature on the topic of conscience. In this chapter I explain the decision to use narrative inquiry to explore conscience in the context of a particular healthcare service, and provide an outline of the methods employed to address the following research questions:

- (1) What are the experiences of team members who have been directly involved in decisions that engage their consciences within the culture of palliative care?
- (2) How do palliative care providers describe the deliberative processes used at personal, professional and team levels, regarding end-of-life care?
- (3) What part of the deliberative processes described by palliative care team members contributes to the successful mediation of conscientious disagreements between healthcare professionals and patients, as perceived by the healthcare professionals?
- (4) What aspects of palliative care providers' deliberative processes provide insights that inform the development of policy and/or reflections on the practices of professionals in other areas of the healthcare system?

This dissertation research was enacted in three distinct phases. First, I conducted individual interviews and a focus group with members of the Saskatoon Health Region's (SHR) palliative care team. Second, I presented an analysis of these interviews to two interpretive panels comprised of management and leadership from the SHR and select health sciences colleges from the University of Saskatchewan. Third, the data collected from the interviews, focus group and

the interpretive panels were analyzed and used to provide findings in response to each of the research questions in the context of the literature discussed in Chapter Two.

### **A. Understanding the World Through Narrative**

As noted in Chapter Two, every person requires the freedom to form a coherent life narrative. This narrative is formed through a person's experiences, which are lived in relationship with others (Clandinin and Connelly 2000, 2) and impacts both the development and the expression of her conscience. Although conscience cannot be observed directly, its expressions may be observed through a person's description of the deliberative processes she employed during significant moments in her life narrative.

Expressions of conscience are particularly evident in the context of healthcare where professionals learn by reflecting on their experiences (Schon 1984) and pass their knowledge on to others through stories. As Kathryn M. Hunter explained, "medicine is filled with stories" and can be "characterized by its dependence on narrative" (as quoted in Mishler 1995, 112). In addition to transferring information in training and in professional-patient relationships, these stories allow healthcare professionals to articulate the deliberative processes in which their consciences are active.

To capitalize on the strengths of healthcare professionals as persons who experience the world through stories, my research has used the qualitative method of narrative inquiry. Although narrative inquiry can be described in different ways, generally this methodology is used to enable researchers to study the meaning found in the stories people share about their lives. As narrative analysts, Jean Clandinin and Michael Connelly (2000), emphasized that, "narrative inquiry [is] a way to study experience" (188). In keeping with this assertion, I used narrative inquiry to study my participants' narratives as well as my own, and found that this

approach enabled my research to delve into the deliberative processes described by healthcare professionals and teams. As findings presented in Chapters Four, Five and Six demonstrate, narrative inquiry opens avenues for observing expressions of conscience in their natural environment: in the web of experiences and relationships in which healthcare professionals make decisions. Further, this method helped me to understand the deliberative processes of palliative care as a unified whole, rather than as a series of isolated events or skills.

My experience as a hospital chaplain uniquely equipped me for this narrative inquiry into the deliberative processes of healthcare professionals. While completing a unit of the Clinical Pastoral Education (CPE) program, which provides chaplaincy training, I conducted verbatim case reports that enabled me to reflect on my experiences with patients and incorporate these experiences into my personal life narrative. This experience provided me with an insider's view of the learning process that is active throughout healthcare and helped me to develop the active listening skills I needed to fully explore the stories presented by the participants in this study.

The acute care hospital at which I worked as a chaplain housed the palliative care services for the region, providing me with opportunities to witness, first hand, the importance of narrative in end-of-life care. In addition to the general prevalence of narrative in healthcare training and professional-patient relationships, narrative has a powerful impact on palliative patients who are in a unique position to reflect on their lives. For example, patients who are able to share their life experience through legacy activities report positive outcomes, such as improved breathing and reduced stress for their caregivers with whom they share their stories (Allen et al. 2008).

Capitalizing on the prevalence of narrative in healthcare, my research relied on narrative inquiry to examine the deliberative processes of healthcare professionals and teams in palliative



care. This approach drew on the strengths of healthcare professionals as persons who learn and communicate through stories, particularly when addressing the challenges found at the end of life. Narrative inquiry had the added advantage of providing a means to explore expressions of conscience within the person's coherent life narrative, as described through individual and team accounts of the deliberative processes used in palliative care.

## **B. Research Methods and Analysis**

As indicated, this study was conducted in three phases following approval of the proposal from my Dissertation Committee, ethics approval from the Behavioural Research Ethics Board of the University of Saskatchewan, and operational approval from the Saskatoon Health Region. In the first phase, which was designed to respond to all four research questions, I conducted a series of interviews and a focus group with members of the Saskatoon Health Region's (SHR) Palliative Care Services's (PCS) team members and analyzed the data collected. In the second phase I reported these findings to two interpretive panels (Noonan 2002) who proposed responses to research questions #3 and #4. The third phase included the crystallization of data collected in the first two phases to respond to the research questions in the context of the literature discussed in Chapter Two.

### **Interviews and Focus Group with Members of the Palliative Care Team**

To elaborate, in the first phase of my research I conducted a series of individual interviews with members of the palliative care team over a period of ten weeks, followed by a focus group one month later. This enabled me to collect data such as records of the experiences and perceptions of members of the PCS team. To initiate my research, I made contact with the medical director of palliative care, who introduced me to the palliative care manager. The palliative care manager gave her approval for the research to be conducted with members from

the palliative care team, which includes the palliative care in-patient unit, palliative homecare, team members who provide consultations throughout the Health Region in acute care facilities and long-term care homes, and some team members who provide support at the Cancer Clinic Pain and Symptom Management Centre.

During my first round of recruitment, the palliative care manager invited me to attend three team huddles with staff nurses and one team-rounds meeting that included a broad sample of team members. I created a recruitment poster (see Appendix A) to attract participants and encouraged those team members to share the poster with their colleagues. The poster was also posted on a communications board on the unit. This method of recruitment attracted two interview participants to the study.

Following this initial round of recruitment, an additional seven interview participants were recruited with the help of the medical director of palliative care, who approached each participant to seek their permission before placing them in contact with me. This initial set of nine participants further recruited one other interviewee, resulting in a total of ten interviewees. However, one interviewee withdrew from the study after viewing her interview transcript. Fortunately, this participants' withdrawal occurred during the interview phase of the study, and another team member who had previously expressed interest to the director of palliative medicine joined the study. One other participant was contacted through a personal connection with a member of the research team. In total, twelve participants were interviewed, and eleven interview transcripts were included in my research.

The participants were intentionally chosen to ensure the perspectives of team members from a diverse range of professions were included. This provided a comprehensive understanding of the deliberative processes used by the team as a whole. The eleven interviewees

whose interview transcripts were used in this study include: three physicians, three nurses involved in nurse management, two allied health professionals who provide psychosocial support, and three persons involved with bedside care.

Each participant received a Letter of Initial Contact (see Appendix A), which invited the person to participate in the study. Participants were provided with a consent form via e-mail prior to the interview (see Appendix A), which was signed on the day of the interview. The interviews were semi-structured to allow me the freedom to establish a rapport with participants and to explore areas of interest as they arose. The questions that guided these interviews can be found in Appendix B. The interviews were conducted over a period of ten weeks.

Each interview was approximately one hour in duration to ensure the experiences and perceptions of each interviewee were explored in depth. Interviews were held at a time and location of each participant's choosing to provide participants with an appropriate space to reflect on their experiences and to avoid distraction. Of the eleven interviews included in this study, four interviewees chose to meet in an acute care facility cafeteria, one chose to be interviewed in a personal office, one chose to be interviewed at a personal residence, and five chose to be interviewed at public coffee shops.

The interviews were recorded and transcribed, and were included in the data collection section of this dissertation following release for use by the interviewees (see Appendix A). Each participant was free to withdraw from this study at any point before the interview transcript was released. As mentioned previously, one participant withdrew after seeing the transcript of her interview. Following their interviews, two participants were contacted by e-mail to clarify their responses.

Following the interviews, the eleven participants who released their interview transcripts were asked to participate in a focus group designed to explore the perceptions of the collective deliberative processes of the palliative care team. Six team members were able to attend the focus group, which included a representative cross-section of professions. Participants were provided with a consent form via e-mail prior to the focus group (see Appendix A), which was signed on the day of the focus group. This group convened for a little over one hour at a health region facility, and was guided by questions that arose following the individual interviews (see Appendix B). Each participant was free to withdraw at any point before the audio recording device was turned on, at which point participants could leave the session but were unable to withdraw comments previously made. The session was recorded and transcribed.

### **Interview and Focus Group Data Analysis**

As anticipated, the word ‘conscience’ did not resonate with participants, and the narrative methodology used in my research was used to explore expressions of conscience that are by their nature relational and must be understood in their context. In their interviews, participants were prompted to share experiences in which they disagreed with a patient or experienced moral distress. Many of the experiences shared following these prompts included an ethical dimension that led participants to share their deliberative processes, including their expressions of conscience. Additionally, at the end of each individual interview and during the palliative care team’s focus group, participants were asked to reflect on the role of conscience in their work, which also resulted in participants sharing stories that detailed their deliberative processes at times of ethical disagreement.

The data collected from these interviews and the focus group were analyzed following the model of “storytelling in interactional and institutional context” identified by Elliot G.

Mishler in his typology of narrative analysis (111-114). This model of analysis focused on the context in which a story is told and emphasized “the socially situated features and effects of stories” (112). This model was particularly useful in this dissertation because the stories shared by participants emphasized the relational dimension of ethical decision-making, as most participants described the deliberative processes they shared with their team members and patients as well as their personal decision-making tools.

Within this model, the conscientious decision-making processes that underpin the stories of palliative care team members were teased out using the coding process outlined by Strauss and Corbin (1990). First, as I interviewed participants, three major themes emerged when interviewees were asked to identify their major decision-making tools: clear communication, collaborative teamwork, and a holistic approach to care. As these themes emerged, interviewees were asked to clarify the tools that were used in each theme and to describe the relationships among the healthcare professionals, patients and family members involved in decision-making. Following completion of each interview, I used the qualitative data analysis software NVivo to create a transcript. As I continued to interview participants, I used NVivo to review previous transcripts and to analyze the stories shared by participants with particular attention to the relationships present in the culture of palliative care and the role of conscience. In NVivo, I was able to highlight sections of text in each transcript and code these sections according to approximately thirty themes that I identified in the research. During this open coding process, I amalgamated these sub-categories into the three themes previously mentioned. For example, during the initial coding I had two separate nodes (or categories) for communication among team members and communication with patients and families. These nodes were eventually amalgamated under the theme of clear communication.

Three themes for the deliberative processes of palliative care (clear communication, collaborative teamwork, and holistic care) were then presented to the palliative care team focus group, the members of which commented on the relationships between the themes and provided more detail concerning the role of relationships and conscience in their individual and team deliberative processes. The eleven interview transcripts and the focus group were then analyzed in NVivo using the process described, and two more themes emerged: real relationships and engaged consciences. This established the five themes for the deliberative processes of palliative care described in this dissertation, and I continued my analysis by using axial coding to tease out the connections between the themes and to categorize the potential transferability of the tools of each theme to other areas of the healthcare system. During this axial coding, the selections from the transcripts that were previously coded were recoded to show overlap between the different themes and to categorize tools that could or could not be used in other areas of the healthcare system. The palliative care team's comments and stories that evidence the five themes for the deliberative process of palliative care are presented in Chapters Four and Five.

### **Interpretation of Analyzed Data by Interpretive Panels**

In the second phase of my research, the results of the data collection and analysis in phase one were reported to two interpretive panels. An interpretive panel is similar to a focus group; however, rather than being used to collect data, interpretive panels bring together experts consulted to analyze data that has already been collected (Noonan 92). The analyzed data from phase one informed the purposeful selection of two groups of four members each of the SHR's management and senior leadership, some of whom also had roles as health science educators at the University of Saskatchewan (see Appendix A for Letter of initial contact). The first panel was selected from the acute care facility that housed the palliative care unit, while the second

was taken from the SHR more generally. These panels each convened for one hour at a health region facility to explore the themes outlined in phase one. Participants were asked to provide feedback on the content of the palliative care interviews and focus group, to discuss their meaning in the larger context of the health region, and to explore their relevance for policy creation in the Health Region.

Each participant received a Letter of Initial Contact (see Appendix A), which invited her to participate in the study. Participants were provided with a consent form via e-mail prior to their interpretive panel's meeting (see Appendix A), which was signed on the day of the meeting after a brief discussion of the form. Each participant was free to withdraw at any point before the audio recording device was turned on, at which point participants could leave the session but were unable to withdraw comments previously made. The panels' discussions were recorded and transcribed as part of the data collected in this study.

The transcripts of the interpretative panels' sessions were created and coded using the software program NVivo. As described in the previous section, axial coding was used to reveal the connections between the five themes for the deliberative processes of palliative care, which had been accepted by the members of the interpretive panels as an accurate description of decision-making in the context of palliative care. Axial coding was also used to analyze the potential transferability of the tools present in each theme to other areas of the healthcare system. During this process, the text of the interpretive panel transcripts was coded under each of the previously identified five themes. The findings of the interpretive panels are presented in Chapter Six.

## **Response to Research Questions**

In the third phase of this dissertation, the findings gathered in the first two phases of data collection were used to answer the research questions. This discussion, which can be found in Chapter Seven, incorporates the findings into the larger context of the literature discussed in Chapter Two and includes further implications for policy development.

## **C. Ethical Considerations**

As indicated, the data collection was conducted following approval from the Behavioural Research Ethics Board of the University of Saskatchewan. The interviews, focus group and the interpretive panels presented minimal risk to participants, all of whom were professionals who are experienced in dealing with the emotional challenges of healthcare. Participants from the palliative care team were free to withdraw from the research at any time before they released the transcripts of their interviews, while members of the focus group and interpretive panels were free to withdraw any time prior to the beginning of their respective group's meeting.

The confidentiality of participants was protected throughout the research process, although this protection was limited. In phase one, confidentiality was limited because the palliative care director and manager assisted in the selection process and because there were relatively few palliative care team members from which to choose participants. In both phase one and phase two, I could not guarantee confidentiality among the members of the focus group or the interpretive panels. However, in an effort to maintain anonymity, in my dissertation participants have not been identified by name and I have made an effort to avoid identifying them by their profession. Although my research involved both male and female participants, all participants will be referred to with female pronouns to protect anonymity. Separate consent



forms for interviewees, members of the focus group and members of the interpretive panel can be found in Appendix A.

An executive summary of findings was promised to participants, to be delivered after approval of my dissertation. Data are securely stored on a password protected thumb drive and the University of Saskatchewan's Cabinet (an electronic storage system). These data will be destroyed after six years.

More detailed information on the ethical considerations of this dissertation may be found in the Application for Behavioural Research Ethics Review and the supplements to this application included in Appendix C.

### **Summary**

Narrative inquiry was a fitting tool for the study of conscience issues in a palliative care setting because it enabled the researcher to enter into the web of relationships in which participants' experiences are lived. As described, the data collected in this study were obtained in two phases. In the first phase, twelve members of the Saskatoon Health Region's (SHR) palliative care team were interviewed individually as well as in a focus group and asked to share their experiences in palliative care. However, due to the withdrawal of one participant, only eleven of these interviews and the focus group were coded after being transcribed. In the second phase, the analysis of these interviews and the focus group were reported to two interpretive panels selected from management and leadership within the SHR and from the health sciences colleges at the University of Saskatchewan, who were asked to comment on whether any of the deliberative processes used in palliative care may be used to inform policies and practices in other areas of the healthcare system. These sessions were transcribed and coded. The findings from the first two phases are presented in Chapters Four, Five and Six. In Chapter Seven, the

findings will be used to answer the research questions in the larger context of the literature reviewed in Chapter Two.

**Chapter Four:**  
**Palliative Care Team Findings:**  
**Clear Communication, Collaborative Teamwork, and Holistic Care**

**Introduction**

The previous three chapters explored the purpose of this study, selected literature on the topic of conscience, and the methodology for this dissertation. In this and the following two chapters, I will present the analyzed data collected using the methods detailed in Chapter Three. This chapter and the following chapter will present the findings of the interviews and focus group with the palliative care team, and Chapter Six will present the findings from the two interpretive panels. In Chapter Seven, the findings will be brought into the context of the literature reviewed in Chapter Two.

As outlined in Chapter Three, the data of this study were gathered to provide findings for each of the following research questions:

- (1) What are the experiences of team members who have been directly involved in decisions that engage their consciences within the culture of palliative care?
- (2) How do palliative care providers describe the deliberative processes used at personal, professional and team levels, regarding end-of-life care?
- (3) What part of the deliberative processes described by palliative care team members contributes to the successful mediation of conscientious disagreements between healthcare professionals and patients, as perceived by the healthcare professionals?
- (4) What aspects of palliative care providers' deliberative processes provide insights that inform the development of policy and/or reflections on the practices of professionals in other areas of the healthcare system?

In this chapter, I will provide a description of the palliative care team and introduce the findings gained through interviews and a focus group with team members. These findings are separated into five themes, three of which (clear communication, collaborative teamwork, and a holistic approach to care) will be presented in this chapter and two of which (real relationships and engaged consciences) will be presented in the following chapter. The referencing system for quotations used in this chapter will be employed throughout this dissertation. The letter “I” and a number indicate quotations from interviewees’ individual interview transcripts (e.g., I1 for Interviewee 1). The letters “FG” precede quotations from the palliative care focus group transcript (e.g., FG I3 for interviewee number 3 speaking during the focus group). The six-digit number following each quotation indicates the time on the transcript for each reference. I have referred to all participants by female pronouns regardless of their gender, and I have avoided referring to participants by their professions whenever possible. Although this diminishes the rich detail to be gained from the participants’ stories, it is necessary to safeguard their anonymity given the small size of the palliative care team.

### **The Saskatoon Health Region Palliative Care Team**

Over a period of ten weeks, I conducted twelve interviews with individual members of the palliative care team; after the withdrawal of one participant, eleven of these interviews were used in my research. Following the individual interviews, I met with six interviewees for a focus group that responded to questions arising from the interviews. The questions and handouts for these data collection sessions are in Appendix B. In the sections that follow, I describe the palliative care team and present five themes that emerged from my analysis.

At the time of my research, the Saskatoon Health Region (SHR)’s Palliative Care Services (PCS) were provided by a team of healthcare professionals that included physicians,

nurses, and allied health professionals. As in Figure 4.1, direction of the team fell under a leadership dyad of its director and medical directors (FG 00:00:34 – 00:10:20). Although some of the healthcare professionals identified in Figure 4.1 worked exclusively with palliative care, others worked only part-time with the team and were involved in other areas of the Health Region. The palliative care team provided services throughout the Health Region and could be roughly divided organizationally into three groups: the team members who reported to the manager of palliative care services, the team members who reported to managers outside palliative care services, and the palliative care physicians.

Figure 4.1: Palliative Care Team Structure

worked on the palliative care unit, as well as the music therapist and nurse coordinators. The RNs, LPNs, CCAs, and music therapist were involved in direct patient care, while the nurse coordinators engaged in a mixture of bedside care and administrative duties. The Unit nurse coordinator was responsible for directing patient care on the unit, and the East and West Nurse Coordinators managed consultations in acute care and long-term care facilities in their respective portions of the Health Region.

Some palliative care healthcare professionals were assigned to palliative care services but reported to separate managers. This group included allied health professionals such as social workers, occupational therapists, and physiotherapists, as well as homecare RNs. Additionally, the palliative care team benefited from the services provided by other Health Region departments, such as ethics and spiritual and cultural care who were sometimes included in the team's deliberations for a particular patient.

Medical care was provided by five palliative care physicians who shared the equivalent of a 1.7 full-time physician position. These physicians were predominantly engaged in direct patient care, but they also had administrative duties with two physicians serving as co-medical directors. Although palliative care physicians are not required to have a background in family medicine, all five palliative care physicians with the SHR's palliative care services were family physicians. Other physicians who provided supplementary on-call care also supported the medical services on palliative care.

Although most of these team members worked only part-time with Palliative Care Services, they were still able to combine in a variety of ways to provide care to patients in four locations: on the palliative care unit, in acute and long-term care, in patients' homes, and at the Saskatoon Cancer Centre Pain and Symptom Management Clinic. The most comprehensive

palliative care took place on the palliative care unit where the palliative care physicians were the most responsible physicians (i.e., the physicians who directed patient care). The Unit was purposed to be a short stay unit with twelve private rooms where patients were visited daily by physicians and had direct access to palliative care nurses and allied health professionals. Patients were typically brought to the palliative care unit for pain and symptom management with the intention of their return home. However, some patients were brought to the unit for care at the end of life, while, in rare circumstances, others remained on the unit for longer periods of time.

Given the small size of the palliative care unit, most of the Health Region's palliative care services were provided through the palliative care consultation sub-teams. The East and West Nurse Coordinators managed these consultations, providing initial visits with patients and working in concert with the palliative care physicians in their respective areas. The East Nurse Coordinator was responsible for consultations at two acute care hospitals and nine long-term care homes, while the West Nurse Coordinator was responsible for consultations at one acute care hospital and nine long-term care homes. Some patients who were initially met through the palliative care consultation sub-team eventually moved to the unit; however, many remained off the unit under the care of other physicians. Although these patients had limited access to palliative care's allied health professionals, other healthcare teams were responsible for their care.

In addition to the care provided in acute and long-term care facilities, the palliative care team also served patients who were stable enough to be at home with the support of homecare nurses. Palliative homecare predates the palliative care unit, and although the ten homecare nurses assigned to this area were connected to the palliative care team, structurally they fell under the SHR's homecare. The palliative care physicians were not the most responsible

physician for patients at home; however, they did provide consultations as needed. These patients were also limited in their access to palliative care's allied health professionals.

Finally, patients could also access palliative care through the Cancer Centre's Pain and Symptom Management Clinic. Palliative care physicians provided consult services at the Centre, with a special focus on complications due to cancer treatments. Other members of the palliative care team were not involved in the provision of care at the Pain and Symptom Management Clinic, but in this context the palliative care physicians received support from the Centre's nurses and allied health professionals.

### **Five Themes for the Deliberative Processes of the Palliative Care Team**

During analysis of the data collected from the eleven individual interviews and the focus group with palliative care team members, five decision-making themes emerged: clear communication, a collaborative team approach, holistic care, real relationships, and engaged consciences. While identified independently in some situations, these five themes are inextricably intertwined and best understood as interconnected and working in tandem. As shown in the sections below, the tools (i.e., the specific skills, techniques and deliberative processes used by the team) that fall under the first three themes (clear communication, a collaborative team approach, and holistic care) were the most easily observed and helped the palliative care team to achieve their primary goal of providing exceptional care to patients and families. These first three themes are presented in this Chapter, while the final two themes (real relationships and engaged conscience) are the subject of Chapter Five. A discussion of the relationship between all five themes is contained in Chapter Six.



## **Theme A: Clear communication**

During my interviews and focus group with the palliative care team, clear communication was the most easily observed of the five decision-making themes identified in my research.

These skills went beyond the ability to articulate thoughts, and encompassed a greater capacity to create an environment in which healthcare professionals, patients and families were free to communicate. For example, one team member shared a story that exemplified her colleague's skill in this area:

I remember sitting in a family meeting with one of the patients that was shooting up in one of the lines we provided for them. She brought the unit to our knees, this patient and her family. And I remember sitting in a family meeting with one of the physicians – who is phenomenal. And this patient – part of why she ended up in palliative care was because she didn't follow treatment plans, she didn't show up for chemo, you know all those sorts of things. And as the physician was going through her history regarding this particular cancer, and going through: "You were diagnosed such-and-such, you had this, you had that." And so many of us – me especially – would be tempted to say: "And you didn't show up for chemo, and you didn't show up for radiation, and you refused this, and you fired your this, and you did this and you did that." She didn't say any of that. [.....] She said, "you weren't able to complete your chemotherapy. You weren't able to start your radiation." Which is saying the same thing, but it's saying it in such a different tone. And to say it the first way – in that, "you didn't show up," – in other words what you're saying to the patient is, "this is your fault, lady. [You made your bed, now you lie in it,]" which would accomplish nothing. It would accomplish you saying, "ha ha. You did this to yourself." But it's not going to help the patient [...], at all. They know they didn't show up for their chemo. They know they didn't show up for their appointments. They know that. The family probably knows it too. So you're not going to accomplish anything; you're just going to put a wall between you and the patient and family, and what good is that going to be? Absolutely none. (I3 00:44:12)

As this story demonstrates, the members of the palliative care team exhibited the ability to communicate clearly both among themselves as well with the patients and their families. This section will explore the communication in these two sets of relationships, and highlight some of the communication skills employed by palliative care team members, as well as the unique features of palliative care that were perceived to contribute to the team's abilities to communicate clearly.

## **Communication Among Palliative Care Team Members**

In large part, the palliative care team was able to provide holistic care to the people they served because they valued opportunities for both formal and informal communication between members of their team (FG 00:10:20 – 00:20:42). The formal opportunities for communication among team members began on the Unit every morning with the nursing handoff when the night shift nurses recorded their patient reports. These recordings were then heard by the daytime nurses, who had an opportunity to consult with the night shift nurses before coming on duty. Following the first team handoff, the nurses met twice a day, once in the morning and once in the afternoon, for a 5-10 minute team huddle to discuss patient care. In the evening, there was a second nursing handoff, which followed the same pattern as the morning handoff.

In addition to the nursing staff meetings, a small group of team members met for a daily morning report. At this meeting, the palliative care physicians were typically joined by the nurse unit coordinators, social worker and music therapist, although attendance at this meeting varied depending on availability. This meeting also often included phone calls from the nurse coordinators at other sites. The morning phone call was seen as particularly valuable for team members who did not regularly work on the Unit:

I try to make time for that phone call, because I like hearing what's going on and what's happening with the patients - and where our patients would fit on the wait list to get onto the unit, and how that interaction goes. Hearing about patients at home - because again I'm thinking sometimes my [...] patients pop up in those conversations too. So I think it's important that we're all talking to each other.  
(I10 00:57:29)

Typically, this meeting was followed by the physicians' bedside rounds on the Unit.

While these daily meetings updated a core group of team members on the daily status of patients, most team members relied on charting (I8 00:14:58) and weekly interdisciplinary team rounds to inform the larger team of broader patient concerns throughout palliative care services.

At these meetings, the palliative care team would meet for one hour to provide updates on patient care and transfers. All healthcare professionals involved in palliative care were invited to these meetings, which were typically attended by physicians, nurses, the social worker, the music therapist, and other support staff such as occupational therapists and physiotherapists.

A palliative care physician went to the homecare office every week for a half hour meeting with the homecare nurses. This meeting would include an education session for the nurses and provide an opportunity for them to explore any concerns with the physician. One participant described these meetings, saying,

It's really good for [the homecare nurses] just to be able to connect and actually talk – troubleshoot [...]. Even a heads up on what's going on makes [the nurses] feel really connected to the team. (FG I11 00:18:40)

This connection was viewed as particularly helpful for new nurses as it introduced them to the palliative care physicians, whom they would call on for support (FG I12 00:18:56).

Although formal communication was frequent, some team members suggested other opportunities for team meetings could improve communication. One team member expressed a desire for bedside report with patients on the Unit rather than the recorded nurses handoff (I6 00:38:47), while another focused on the absence of the monthly palliative care operations meeting. This meeting had provided an opportunity for team members to connect and discuss bigger picture items, such as the development of a new hospice. Some team members expressed a desire for these meetings to continue, with one participant stating,

I honestly have no idea what's happening at [the other facilities]. [...] I have no idea what's happening in hospice – nothing, we don't know any of that anymore. I didn't even know we have a new director until [a palliative care physician told me that and then brought her up yesterday]. (FG I3 00:20:13)

Team members assumed the operations meetings were canceled in an effort to cut back on meetings that are not directly related to patient care.

In addition to these routine opportunities for communication, team members also communicated informally as necessary throughout the day (FG 00:15:19). Team members both on and off the unit felt comfortable contacting one another and making themselves available to others as needed (I1 00:50:50; I5 01:04:24). The palliative care team's physicians were singled out by other team members as being accessible, especially when compared with physicians on other units. This was recognized to be a product of the presence of the physicians' offices on the unit (I2 00:23:42), the open demeanor of the physicians themselves and the reliability of the physicians' on-call system (I11 00:35:43).

Participants stressed that every healthcare professional was valued on the palliative care team (I3 00:54:58). As one team member said: "in palliative care it's such a different environment that you don't feel like anybody's less because of their vocation" (I1 00:00:56). In addition to ensuring that the voices of the team members who spend the most time with the patient are heard (I6 00:46:22), the palliative care team's emphasis on team communication also facilitated communication between the team and the family (I2 00:45:46). One team member explained:

I guess sometimes if we think it might be difficult, we meet as a team ahead of time - make sure everybody's on the same page. [...] I'll say to [the nurses that are caring for the patient], "hey, we're having a family meeting. Do you guys think it's appropriate for Mr. So-and-so to go to a nursing home?" And I'll get their take on it because they're the ones that care for the patients. They're here 24 hours a day. They intimately know the patient; they know what they can do [...]. So I try to get their input if I already don't know it, and then often the team will meet a little bit ahead of time and just make sure everybody's on board with it because the worst thing you can do is go into a family meeting and give them three different opinions from three different care givers! (I3 00:32:41)

This open team communication also provided team members with an automatic second opinion, which was seen as particularly valuable in challenging situations (I11 01:02:50). This communication promoted input from team members to improve patient care (I3 00:50:45) and

personal performance (I9 00:38:06), as well as to manage situations that may have been causing moral distress (I8 00:34:14).

Communication among healthcare professionals also extended beyond the palliative care team. Team members needed to link patients with resources within the hospital, such as physiotherapy or occupational therapy, or with resources in the community (I3 00:00:35). Additionally, team members who worked outside the palliative care unit, in homecare or providing palliative consults, collaborated with family physicians and with the cancer clinic as well as with other teams throughout the Health Region (I11 00:21:46). Clear communication with other healthcare teams was particularly important for the consultation sub-team in its support of the work of other physicians who may not have any expertise in palliative care (I9 00:49:26). In these situations, team members saw themselves as facilitating end-of-life care conversations and aiding the healthcare professionals who were closest to the patient (I9 00:49:26; I9 01:12:44).

### **Communication Between the Palliative Care Team and Patients and Families**

Palliative care team members tried to engage in conversations with patients and families as much as possible (I2 00:22:47). For example, communication with patients and their families were formal, through intake interviews and family meetings, or informal. When communicating with families, the palliative care team tried to include as many family members as desired by the patient, paying special attention to coordinating the team's interactions with the patient and clarifying the goals of palliative care.

When a patient was first connected with palliative care services, a member of the team would meet with him or her to conduct an intake interview. This interview was conducted by a nurse coordinator if the patient was in an acute care facility but not on the Unit (I9 00:22:01), by

a bedside nurse if the patient was brought to the Unit (I6 00:11:35), or by a Client Patient Access Service (CPAS) coordinator and a homecare nurse if the patient was at home (I11 00:20:26). The intake interviewer charted key points, such as a patient's mobility or pain concerns, to communicate the patient's history and needs to the rest of the team (I6 00:11:35).

The palliative care team would make an effort to coordinate the team's introduction to the patient. For consultations and patients on the Unit, palliative care physicians thoroughly reviewed the intake interview notes along with the rest of the patient's chart, paying close attention to other physicians' notes to ensure that patients and families have properly understood their diagnosis and prognosis (I12 00:14:10), a process that would be facilitated by the adoption of electronic medical records (I12 00:14:33). Participants stressed that the palliative care team limits the number of times patients are asked to repeat themselves. One physician explained:

If they've come during the day, most often I'll let the nurse meet them first before I take a quick handoff summary - so I don't have to [...] ask the same questions. I think that's one thing in healthcare people detest - that you're asked the same questions over and over and over again. And when you're sick - or when you come into palliative care - that's the last thing you want to be asked is what year you had your gallbladder surgery or your eye surgery. "I've already given all that. Couldn't there be a record of it somewhere?" (I12 00:12:56)

For their part, palliative homecare tried to limit the number of times patients were asked the same questions by sending a homecare nurse with a CPAS coordinator, who is responsible for the coordination of care for homecare patients, for a patient's intake interview (I11 00:20:26).

Participants shared the importance of ensuring that both the patient and the team understood the goals of care at this initial stage. While team members made every effort to communicate the holistic focus of palliative care verbally, the philosophy of palliative care was often communicated to patients in other ways:

Often times we'll go in a room and sit down and spend time with a patient, hearing about their life and what's happening for them. I'm not saying that my other

colleagues don't do that, but internal medicine doctors who have a roster of 30, they just don't have the time to do that. So I think [patients] perceive quite quickly that we have a different focus. I think it's subtle. It's not necessarily that we'll walk in and say, "okay, we care about your experience and your family. Please tell me about that." (I10 00:12:36)

Although the philosophy of palliative care was present throughout their work, team members were sensitive to the impact the word 'palliative' care can have on patients and families, making an effort to avoid that term in some situations by focusing on their role as pain specialists instead (I7 00:08:29; I11 00:16:26). Beyond communicating the general approach of palliative care, the team also ensured the goals of care were discussed and the patient's wishes regarding pain management and interventive care were known, providing an opportunity for patients and their families to voice any concerns they may have had (I2 00:34:43; I5 00:55:07; I7 00:15:04). One participant clarified this patient-centred approach to setting goals, saying:

So, to create a care plan and an agenda is not patient-centred. So, it's important to know not only what our goals of care are, but most importantly what is the patient's. When they were admitted, what are the issues that were of most concern to them. And to check to see: Do we know what their goals of being admitted are? What are their concerns or their worries? And what are staff's? I think that is a huge piece, so making sure that that has some reflection is important. (I2 00:33:42)

Some team members stressed the importance of addressing the patient directly (I6 00:29:21) rather than talking about them in the third person, and others emphasized that the team took patients at their word, particularly when the patient was describing his or her pain (I2 00:04:11; I12 00:11:35). The goals of palliative care are further explored in the *Holistic Care* section of this chapter.

The palliative care team relied heavily on bedside visits and family conferences to communicate with patients and their families. The consultation sub-team generally visited patients in their hospital rooms with as many family members present as possible (I10 00:16:19), while on the Unit, bedside rounds were conducted routinely most mornings. Although these

meetings addressed most concerns, such as medication changes or revisions to the treatment plan (I3 00:09:19; I5 00:28:53; I12 00:17:41), family conferences were called for patients throughout palliative care services to address more specific concerns. These meetings often included a discussion about the next steps for a patient, particularly when a patient was no longer suited for the short-stay palliative care Unit (I12 00:25:41) and were often led by social work, with great input from physicians as well as other team members, as needed (I3 00:35:25). One participant explained the team's approach to family conferences, saying:

[We invite] whoever wants to be there because they have lots of questions. We're giving out our card so that whoever wants to be part of this discussion [about] care - whoever it might be - can be a part of that. It's the long distance siblings or children or parents or whatever that have a hard time with stuff sometimes. But it's a whole family discussion - answering those questions and explaining our role and the support system. (I11 00:21:46)

These meetings enabled family members to give more information, especially if the patient was ill or confused about their history (I12 00:12:56); however these meetings also provided an opportunity to speak to the wellness of the patient, focussing on the things the patient can still do (I12 00:26:21).

Participants also emphasized the importance of providing their patients with accurate information to enable them to make good decisions about their care (I5 00:57:19; I12 00:38:43). Often this information was provided to patients during formal meetings. For example, when advanced care directives were discussed during intake interviews (I7 00:17:44; I11 00:43:42). However, the team cautioned against overloading patients with too much information when they were first introduced to PCS (I12 00:15:28). One team member explained:

I think what our physicians are good about - and I think the whole team - about making sure that if we're not talking about something it's not because we're uncomfortable talking about it. Respecting that people have the right to take in as much information as they want to or not, but that we have a responsibility to at least check to see where they're at with receiving information. (I2 00:34:43)



Another team member stressed the importance of having patience with patients and their families when trying to give them information regarding their care:

A lot of times it just takes a lot of patience and talking and explaining pros and cons. I find a lot of times if you take that time with patients and families and really give them a good review of pros and cons, most people don't want things that are going to increase their suffering. (I10 00:27:43)

Other team members also emphasized that when given accurate information, patients tended to make good decisions about their care (I11 00:45:25). In situations where healthcare professionals and patients did not agree on the best course of action, team members felt it was important to find middle ground with families. One team member explained:

[A palliative care physician] taught me early on that sometimes we know treatments are futile, but you may bargain with family for, say, three days trial of a particular treatment. If I don't think it will harm them - then to bargain with a family for two or three days to try something. And then we ask the patient and family, "did that make any difference?" We do that with blood transfusions: "Do you feel any stronger? Any better?" Sometimes the patient the first time of trying a treatment will say, "yes, I think it helped," because their loved ones want them to feel better. And then the next time round they'll say, "you know, I don't think it really made much difference." So I think just having the patience to hold that tension with families. (I12 00:23:39)

This participant also shared the challenges of finding common ground with patients who wished to use alternative medicines:

[An example comes to mind of] an individual who really struggled with conventional medicine - who was really an advocate of alternative therapies. [....mild interruption.....] So getting buy-in - or giving clear and strong enough information to allow that individual to be less scared about what I was offering with conventional medicine. [Alternative medicine] is great when you don't have outrageous pain - outrageous physical symptoms. [Alternative] medicine - including meditation - is rather hard to hold focus to when the symptoms are raging. And I think that leads to moral distress; I think that leads to family dysfunction/distress. That's the first one that comes to mind, and it would be a common one. People struggling with: "oh, I've got to take more medicine?" And then explaining why I'm adjusting the meds, or why the nurses have come and suggested that we make an adjustment. Once we near the end of life, often families are just relieved that their loved one is cared for, so: "do what you need to do to keep him comfortable." But especially at that front end, it's that tug-o-war. (I12 00:18:44)

She further elaborated that although she was not trained to work with complementary medicines, she was “not oppositional to them” (I12 01:05:42) and further emphasized that “coming at it with a hard hit,” (i.e., demanding the patient follow the doctors orders) was ineffective and damaged the team’s relationship with the patient (I12 01:14:17). Another participant stated that if a patient or family member was having a difficult time accepting a prognosis, she would “nudge it along a little at a time” (I11 01:02:50) to patiently help the person accept their situation.

### **Communication Skills and Other Factors Unique to PCS**

The palliative care team’s ability to communicate clearly was facilitated by the skills of individual team members as well as by other factors to unique to PCS. These factors included the team members’ verbal and non-verbal active listening skills, as well as the time and space afforded to patients and families on palliative care.

Palliative care team members described their skills as a blend of natural and acquired abilities. Team members acknowledged that they were good communicators before arriving in palliative care (I12 01:00:17), and that the work done on palliative care attracted people who possessed strong interpersonal skills (I10 00:22:32). On the subject of whether these skills could be learned, one participant stated that she believed that while “the finesse in all of medicine” could not be learned, it could be developed with the help of “wise mentors” who can identify helpful and unhelpful skills or habits (I12 01:17:48).

Team members also identified many active listening skills that could be learned by anyone. For example, if a team member were to receive a request from a patient or family for something she felt she could not provide, rather than saying “no,” she would ask a question to invite further conversation, such as, “tell me more about why you’re requesting this” (I12

01:10:48). One participant stated emphatically: “That’s the thing – it’s not just a ‘no.’ It’s generally a conversation – it opens the door to a conversation” (FG I6 01:01:14).

Palliative care team members reported making a concerted effort to use language that was accessible to the patients and that created an opportunity for open communication. The team’s physicians were singled out by one team members as being particularly good “at taking very complex medical situations and distilling them into a language that was accessible [and understandable]” (I2 00:04:11). As one team member explained, word choice was also important when discussing patients who are healthy enough to leave the palliative care unit:

I actually, in family meetings, try not to use the word stable because that's kind of a silly thing to talk about with a terminal illness. So I talk about them being as good as what we feel they can be at this moment with the disease they have. And that they don't need the care of the palliative care unit. Absolutely they need care. Without a doubt they need care. But they don't necessarily need the acute palliative unit. And sometimes if you phrase it that way and acknowledge that they need care - up front - and acknowledge that they can't be looked after at home - if you know that already - and say what a wonderful job they've done so far, but that now we need to look at care elsewhere. And sometimes that works, sometimes it doesn't. (I3 00:32:41)

Finally, word choice was identified as an important tool for connecting with patients. For example, communication was improved by asking, "how many children have you had?" rather than, "how many children do you have?" (I12 00:58:40) to acknowledge the relationship between a parent and a child who had passed away.

Participants also stated the value of open, honest conversations. One participant related an occasion when the direct approach was particularly valuable for her, saying,

In that particular situation - again this was a respiratory issue and respiratory issues are just hot topics because they're very panicked, and - you can't breathe! It's scary! But, this family in particular was just raising the anxiety level of this patient all the time, therefore making it much more difficult for the patient to breathe. So every time a staff member would go in there, there was a comment made about, "this family has to back off from this patient." To the point where they're actually hovering on this patient's bed - their faces are [very close to the patient] and, "are you okay? Are you okay?" And really panicking this patient, so I actually had a conversation with the family members a couple

of times that, "I think the best thing to do would be to maybe sit back a little bit. Give her a little air. Let her breathe. Don't ask her all the time." I find the best thing usually is just to have that conversation. (I6 00:30:33)

Another team member, focusing on times when patients needed to leave the unit, stressed the importance of telling families that the palliative care team would keep their loved one if they could and reassuring them that the patient's moving could not be avoided (I3 00:36:51). In another story, a team member explained the value of apologizing for shortcomings throughout the healthcare system:

I mean I've had lots of people come from the unit, lots of patients come [to] the unit that are very disheartened with the healthcare system - like just so angry because according to them - I mean, every story has two sides - their dad or whoever should have been diagnosed and the doctor missed it, and he didn't do enough tests, and then this doctor missed it, and then - you know? And some of that might be perfectly true and some of it might be just their version of it. And they come to us and it might be all we do is sit and let them vent - we listen, and tell them we're really sorry that things went as they did, and we apologize for that - but what could we do now to make things better from now on. And so we're not telling them that didn't happen - you're full of whatever, [or] try to justify any of that - because that's gone by, that's done. What we do is we listen; we don't say, "oh no," and then we say, "okay, let's see what we can do good from now on." And you just see their faces change - like it's amazing, because they come in angry and mad - and they aren't angry and mad at us because they hardly know us. But they've been - in their minds - so disheartened by the healthcare system and in some cases they feel that's why their loved one's dying. And then they come up against us, and we're part of that system so I think they just expect the same from us or that we're going to defend the system and say, "no, that didn't happen." And they get this other response from us, and it's huge because now we can work with them. If we get our backs up and say, "no, that didn't happen," and argue with them, that's going to do nobody any good. That's not going to do the patient any good; it's not going to do the family any good; and it's not going to do the team any good because we'll get nowhere with this patient and family. So, just that encounter. (I3 00:16:37)

In such situations, the palliative care team felt it was important to allow patients to vent their anger without taking it personally (I9 00:35:52).

The team placed great importance on non-verbal communication skills as well. When describing a typical visit with a patient, one participant stated the importance of sitting down, stressing:

It sends the message that I'm not going to rush away. I'm settling in to hear how things are for you. I think that's a big part of it. I make that effort to find a chair every time because I want the patient to think that - sometimes I get called away - but if I'm there, I am there to hear what's happening for them and that's important to me. Rather than rushing back out to look at my lab results or something like that. (I10 00:13:59)

Other participants spoke about the value of smiling regularly, giving a hug, or making the extra effort to communicate with persons who were unable to speak (I1 00:29:48). Another participant noted that, "when language fails, music can come in" (I12 01:00:17). In addition to helping those who had difficulty expressing themselves through words, music also served "as a catalyst in self-expression" (I8 00:22:41), as many patients were ready to share their thoughts after sharing a song (I8 00:20:29).

Team members also stressed the value of a good sense of humour (I1 00:43:14; I9 00:16:33), of being honest when a problem cannot be fixed (I5 00:47:05), and admitting when a mistake had been made (I12 00:23:39). As well there was the need for cultural sensitivity, particularly when working with cultures in which end-of-life conversations are a taboo (I11 00:16:26).

Team members observed that these skills required space and time to be used effectively (I2 00:49:44). While the PCS greatly benefits from the physical space afforded families on the Unit (I2 00:12:57), the palliative care team's main focus was on their commitment to set aside time and emotional space to invite patients into deeper discussions (I2 00:49:44). For example, one team member explained:

It comes down to just talking about things, and just trying to explain what we as clinicians are seeing and what's happening. Sometimes that takes time, as well. Because you can say, "yesterday I noticed this about your mom, and today I'm seeing this." So that change with time is really valuable because most of the time patients and families are seeing the same things you are, they just need to have it clarified that, "yes, this is what it means." Again it comes down to time and trust. (I10 00:30:23)

This emphasis on creating the time and space for conversations allowed the team to direct more energy towards inviting discussion with family members, particularly in challenging situations where the team feels they need to build trust (I12 01:15:51). As one participant shared, this was a source of pride for team members: “I really have to say that I'm so honoured to be part of [a] team that really does make people feel as comfortable as possible in the circumstances - to really hear where they are at” (I8 00:54:41). Team members had also learned when to step back and give patients space away from the team. In tense situations, one participant explained that she had often left families alone for a period of time before returning to give them a chance to discuss their situation (I10 00:31:11). As mentioned in the section regarding communication among team members, the deliberate creation of space for conversations also allowed for greater input from team members who might otherwise not have had a voice (I2 00:45:46).

Clear communication brought with it many benefits, most of which impacted the other decision-making tools used by PCS. The most easily observed benefit of clear communication was that it helped palliative care team members to find solutions for their patients, which could, but did not always, involve more care by the team (I2 00:31:58). One team member explained:

Sometimes there's solutions by just sitting there and listening to their side of the story - because working in healthcare sometimes you get this attitude that, "you're right; they're wrong." But I think sometimes when we listen [we] realize that the patients have a point - that solutions can be found. Other times there's just no way you're going to find middle ground. None. Sometimes those patients get moved off - if they're palliative care; if their needs are so tough; if the psychosocial issues are so tough - then sometimes we will move unhappy families into [the palliative care unit], where things can just slow down because this pace is so fast and there's so many people coming and going out of your room. Other times we have to discharge ourselves. If the issues are such that the families are upset because they disagree with the philosophy of care - we might be the root of their issue. So you end up having to discharge yourself because you can't help. (I9 00:33:54)

Good communication also facilitated building trust (I10 00:22:00; I12 01:15:51), helped team members to see a more complete picture of their patients (I2 00:04:11), and allowed the team to

gauge where a patient was on their journey (I7 00:08:29; I10 00:29:45), all of which contribute to the provision of holistic care for patients and families. This had a profound effect on families after the patient had died as well, as one participant highlighted:

I remember when I still was in family practice, one of the conferences I went to said, "write the death date in your charts - of a really significant loved one - a child, a spouse, a parent. Write the death date down and see if that person that's the remaining individual isn't in within a week or two of that death anniversary with some sort of physical illness." And it's uncanny. It was so true. So you know that whole link between grief and wellness/illness - we have that to teach to the rest of medicine too. (I12 01:04:09)

Finally, good communication energized team members, helping them to engage more fully in their work. When asked about the impact of having open communication among team members, one participant commented:

It's awesome! It gives you so much more input into care and [you] know that you can make a real difference right now. I don't have to wait until tomorrow when you see that I need something for this patient. I'm able to make a big change right now and see if it works. Maybe it won't, maybe it will, but at least in five hours we'll know. (I6 00:47:11)

Participants acknowledged that palliative care services had certain advantages that made communication easier that are not possessed by other areas of the hospital. These included the team's ability to clearly state their goals of care (I5 00:38:55), the Unit's extra space for family rooms and private patient rooms (I2 00:12:57), a lower patient-to-staff ratio than most other units in the health region (I0 00:46:23; I6 00:06:16; I10 00:28:32), and a quieter, more intimate environment (I8 00:40:28). However, they also believed that at least some of these discrepancies could be resolved. For example, discussing the advantage of physical space on the Unit, one participant commented,

There is nowhere in our hospital designs that allows families to be. We actually build hospitals for people to be sick without their families close by, rather than to be healing with their families close by. We build hospitals so people really want to get out of them. (I12 00:11:35)

This participant also noted that hospitals were shifting towards providing more appropriate spaces for healing, observing,

[There's a new unit where] they took an old wing of the hospital and did a beautiful job renovating it - but it has that feeling of [being able to breathe] because it has windows - it has space - each room is not crammed in. (I12 01:01:00)

Other participants felt it would be possible to train healthcare professionals with the communication skills they need to have effective conversations (I10 00:46:23; I12 01:17:48), and to encourage them to engage patients in end-of-life conversations (I9 01:11:10). As has been highlighted throughout this section, these skills were perceived as having improved communication with patients as well as among team members. This, in turn, improved the team's ability to work collaboratively, which is the subject of the following section.

### **Theme B: Collaborative Teamwork**

In the preceding section, many of the stories that evidenced the team's communication skills also provided insight into their collaborative team approach for the provision of holistic care. One participant explained her reliance on colleagues by sharing a story about a complex patient:

We've gotten some patients who have issues with their opioid medications - not necessarily abuse, but maybe misuse. And I find [after getting the perspective of] the nurse who's often the one that talks on the phone with the patients and then getting that social work perspective, [I think], "okay, well, maybe I'm getting a red flag on their opioid abuse because they don't have a stable home life and can't get their prescriptions filled at the same pharmacy. And so that's going to raise a flag, for example. So really having that social worker sitting beside me as part of the team really informs those decisions right away rather than the social worker coming three hours later and reading a chart that maybe [she doesn't] have time read. So I find those relationships among the team really helpful. (I10 00:10:27)

While this story provides a clear example of teamwork in action, another participant stated the value of this approach more succinctly: "palliative care in essence is meant to be a team participative sport; not to be a solo [activity]" (I12 00:26:53). In this section, the discussion of



the team approach used on palliative care services is divided into three parts: the skills and tools used by the team to encourage team cohesion; the attributes of individual members that contribute to the well functioning of the team; and the benefits of the collaborative team approach.

### **Team Cohesion**

Although palliative care team members reported to different managers and many of them were spread throughout the Health Region beyond the Unit, team members reported that teamwork was one of their greatest assets (I12 00:5:08). Speaking in the context of palliative homecare, one participant stressed that a strong connection between team members was essential to the provision of good care for their patients, explaining,

[Our most valuable tool is] strictly the communication. That is one of the biggest keys. The communication - the support from the doctors. The fact that even if we are unsure of what to do - and at times we all are - we can phone the doctor and say, [.....] "this and this is happening. Even if we phone the GP, he's not going to know what to do; what would you suggest?" Even if we don't get the orders from them, we have that support; we have that teamwork. Sometimes the nurses will phone me - some of the newer nurses - and I'll give them suggestions as to what to do. It's just good teamwork and sharing of information. And at the end of the day we're sharing information too - very informally. [And] if you're working the weekend: "oh, yeah..." there will come a twig that, "yeah, I heard about Mr. Jones, even though he's on the East side of the [City] and I work on the West and I have to go see him. I remember hearing about that situation now." I think communication, [...], teamwork - when we're all stressed, [or] we're short staffed sometimes. And a lot of the senior nurses will just step up to the plate, and they'll say, "I think Mr. Jones is doing [well], we maybe don't have to see him. I'll phone him and see how he's doing," or, "I'll take an extra patient." (I7 00:41:01)

As noted in the section on clear communication, the palliative care team had many opportunities for formal and informal communication that helped to build relationships among team members and to encourage open communication. Team members credited the formal opportunities for communication with helping them to feel connected to the team (FG I11 00:18:40), with one participant stating: "It's good we have those [...] morning meetings because then [the

physicians] really feel they know us, I think, and are able to trust us” (I7 00:21:50). These meetings were singled out as being particularly beneficial for homecare nurses because “it's very helpful for [new nurses] to meet [one of the co-medical directors] because then when they're picking up the phone with someone at home and they're calling [the physician], it's so much less threatening when they've already met [the physician]” (FG I12 00:18:56). Frequent meetings also encouraged open communication among team members (I6 00:44:39), giving each team member “space to voice [their] concerns” (I8 00:35:11) and providing “an equal part in their say, to help find potential solutions for patients and their families” (I9 00:46:48). As one team member explained:

For me, probably a lot of it comes down to having a place where there's space for open communication and a difference of opinion. So it is safe to disagree. Ultimately the physician still is responsible for whatever decision is made. I think that we try to - as much as possible - have that discourse, discussion, disagreement, at the front end so that we can have our piece heard or said, and then once a decision is made try to support it and try to make it the best possible piece. And a recognition that none of us likes having conversation about long term care or personal care homes, so that we do tend to try to do that as a team so that it's not just the social worker saying, "we have to look at this alternative living option." The physician and the nurse - we try to have a consistent message with it as well. (I2 00:45:46)

These opportunities for communication also served to ensure “that everybody is supporting each other and that you come in on the same page” (I9 0:46:18), which, as mentioned in the section on clear communication, improved the team’s communication with patients and families (I3 00:32:41).

In addition to making a conscious effort to foster open communication, the palliative care team was intentional in their efforts to strengthen their team cohesion through social events. These ranged from summer BBQs (I7 00:46:00) to staff lunches (I7 00:28:18). One participant explained the value of these events:

At Christmas time one of our nurses [...] makes us a Christmas meal. We don't do any of the work. We come the day before and help her with [chopping] and stuff like that, but [she really does] the [hard] work. So then we're in her home. It's different being in someone's home and mingling. And we always celebrate birthdays. We just do those kinds of things to help keep the team spirit up too. (I7 00:28:18)

These events helped to build trusting relationships among team members, some of whom had been working together since they began on palliative care services (I9 00:39:32). In turn, these relationships helped team members to respond positively to feedback from each other (I2 00:11:48; I3 00:49:06). One team member credited their success as a team to these strong relationships:

I think one of the things we do well in palliative care is - ideally - we work together as a team; we treat each other respectfully. If one of the nurses who is looking after a patient tells me they need something, I'm not going to question her because I trust that person's judgement - usually, I mean if someone really new suggests something outlandish I'm not going to agree. [The healthcare system] is so hierarchical, and I think that's one of the things in palliative care that we really do well. We work really well together. So the nurse that I work with - she calls me every day - sometimes she calls me five, ten times a day - "I think we should do this?" And I say, "good." (I5 01:04:24)

Many team members spoke about the emotional support they had received from other team members, with one participant stating:

I do find a very close team there. And we laugh a lot because we have to sometimes. [We] just enjoy each others' fellowship - and even to laugh about different things - because sometimes it can be very difficult. I mean, all of our patients die at some point, and that is just the reality of it. (I11 00:06:03)

Another participant echoed these feelings:

If you're struggling with a person's situation, or if you feel that there is a psychosocial piece that for some reason I am not able to address, to be able to identify that [it is valuable] to see [how we can] support each other in the work that we do, but as well have it safe to talk about when we feel that maybe there's something more that needs to be done but we don't know exactly what that is. (I2 00:11:48)

The value of these supportive relationships between team members will be discussed in greater detail in the section on real relationships in the following chapter.

Opportunities for communication aided the team in coordinating (I8 00:24:16; I10 00:14:44) and sharing the responsibilities for patient care (I12 00:15:28). As one participant explained:

[My job is to] keep track of where we're going with the patient, both for his physical symptoms but also long range planning if that's appropriate for the patient. Sort of link him in with any resources within the hospital, whether it's physiotherapy, occupational therapy, etc. Although [with] all those things we act as a team, so if I don't remember it somebody else will [remember] to make sure that they have access to the supports that they need in the community if they go back out into the community. (I3 00:00:35)

Another participant described the value of having a cohesive team, stating,

We don't try to force relationships. Sometimes by giving space, you walk with people versus trying to push them or pull them to be someplace where you feel that they need to be or they should be. But you walk with them where they're at, and sometimes - for me - it's giving invitation or different people. Perhaps it is the physician, or the bedside nurse, or the music therapist or the social worker, or the nurse that might make that connection and for me that's okay. Then that person can try to facilitate or expand that network of support. So that it's not one person's responsibility to see that person or to make them feel safe or comfortable - it's everybody's. (FG I2 00:54:46)

Many participants focused on the connection between psychosocial services, such as social work, music therapy and spiritual care, while highlighting that all aspects of patient care needed to be shared by the whole team:

Often it will be in the middle of the night or a bath that a family member or a patient will have a really significant conversation, so that it really is seen as a shared piece that I think everybody holds, not just: "okay, you need to talk, but I'm not going to talk to you. I'll wait till the social worker comes." (I2 00:21:37)

One physician described her reliance on teamwork, stating,

I go and find the social worker if I feel like a family's in major distress, or if I've heard a piece of news that - not to be gossip - but that needs to be held; that needs to be held gingerly because maybe it isn't something that we want to write firmly in the chart notes. People as they die sometimes have big sorrows or they have big regrets. And coming to terms with those is a major component of dying at peace. And so having a social worker on is invaluable. I just wish we had one [all the time] - because she's pulled away so often to do a hundred and one other jobs. [.....] Nursing - I lean into them for what they're seeing hour to hour to hour at bedside. [.....] It is still up to me to look at the whole picture of

medication that the individual is on and say which one would be a good blend for whatever symptom is bothersome in combination with what they're already on. (I12 00:27:48)

Another participant remarked on the cohesion within the team of physicians, stating:

Territory doesn't tend to be an issue in palliative care. I don't know why that would be, but I think as a team we're not - I would say we're not at all territorial. We look after each others' patients. (I5 00:07:11)

Although all participants placed great value in teamwork, some drew attention to the different degrees of team involvement required by different healthcare professionals, with one member of the consultation sub-team stating:

I find [the] intensiveness over [on the palliative care unit] a little bit overwhelming. Too many people making decisions for the same thing and too much responsibility. So, this works very well for me. It's where I need to be. I'm a project girl, so dealing with new and exciting things - like helping the non-malignant cases get a little bit of supportive care - to me is very fascinating. Leading groups and helping groups establish themselves. (I9 00:39:53)

Team cohesion was not uniform across all sections of the palliative care team, but rather it adapted to meet the goals of healthcare professionals, patients and families wherever these might be in the healthcare system.

The importance of team cohesion was particularly evident when the palliative care team was faced with complex or challenging situations (I8 00:12:06). Several participants stressed the importance of drawing on the experience of other team members, with one participant stating

I guess sometimes when things seem very black and white then that's easy. When it isn't, then you need to pull in more information and maybe that's when the consultation might [happen] with another nurse - or another nurse goes out, because sometimes we don't go in as a team. [Sometimes it feels like] we go in as loners - and that's when if it's complicated, it feels like it's a challenge on one set of shoulders. It's nice to be able to consult with a physician - or really another pair of eyes we'll call it - another homecare nurse will go out and say, "you go out this time and let's make a collaborative understanding." Or CPAS may go out and make another visit [...]. When it's complicated and it's not clear, you need the confidence of other people that you are really making the right kind of decisions. [...] Even if you're of the same profession - you need a different perspective, a different understanding [and] a different background. (FG I11 00:27:15)

However, at least one participant preferred to approach challenging situations alone at first, explaining:

I find that [...] either: a) the other team member will take over and then you're viewed in a less trustworthy light; or b) [...] the patient support will feel that we're closing ranks against them. And I don't want that either. (I6 00:18:21)

Although this participant preferred to visit patients alone during tense situations, she continued to value palliative care's collaborative team approach (I6 00:47:11).

Participants from the consultation sub-team and homecare also described their reliance on forming teams with healthcare professionals beyond the palliative care team. Although they considered themselves to be part of the palliative care team, palliative homecare nurses reported to homecare managers, not to the palliative care manager (FG I12 00:05:05). This was likely due to the historical creation of palliative homecare, which formed as an extension of the Health Region's homecare services several years before the palliative care unit was established (I7 00:05:44). Homecare patients were easily shared between the regular homecare nurses and palliative homecare:

Sometimes [patients] are transferred from homecare to us - a doctor referral has come in and they've been pretty sick people but they were seen by the district because they weren't considered palliative, and now they're considered palliative. Sometimes - depending on the nurse that's out there - some nurses are pretty comfortable with palliative and they have a good report with the person already. We may share them [or] the nurse may keep them and just consult us or say, "I'll give them to you when I think it's time." Or we may take them over, they may say, "I don't like palliative care - [I] don't do it well." And we're happy to take it over. Most times we do take it over, but recently somebody came on that has a daily visit from the nurse for an injection. We're not going to take that on, but we're going to see the person twice a week. So we're going to share that person with the district. (I7 00:10:56)

Palliative homecare nurses also coordinated patient care with CPAS coordinators, who arranged admissions and provided guidance when caring for patients with complex needs (I7 00:08:29). In addition to being accustomed with sharing their patients with the Health Region's homecare

nurses, palliative homecare was also at ease accessing community resources. Another participant explained:

We'll have clients that [are] palliative, but maybe they need daily dressings. So [the Health Region's homecare nurses are] out there on a daily basis and we might go out once a week [or] twice week just to cover how they're doing symptom-wise. And maybe once [...] the palliative aspect of it progresses to a point, we might take [the patient] back completely. Or they're under med management and there's someone helping with meds everyday but they're still needing [us to check in]. So there is a lot of collaboration going on and [we] certainly seek the resource team a lot - dietician a lot, physio, OT - all those community resources a lot. But the regular homecare nurses do share clients a lot. (I11 00:23:51)

The palliative homecare team also built relationships with the family physicians responsible for care when patients were in the community and with the cancer clinic:

We work very closely with the GPs - or try to - calling them and letting them know what's going on and changing medications if that's what's needed - and with the cancer clinic. Often more so directly with their nurses than with the oncologist directly - but with their nurses. And now with the symptom management team at the cancer clinic also. (I11 00:21:46)

These teams were particularly valuable for palliative homecare because although they were connected to the palliative care unit through their relationships with the palliative care physicians with whom they consulted, they remained at a distance from the core team both physically and hierarchically.

The palliative consultation sub-team was in a similar situation as that described by palliative homecare, insofar as they were physically removed from the palliative care unit. As such, the nurse coordinators and physician who conducted consultations in long-term care (I9 00:40:47) and on other units in the hospital were focused on building relationships with other care teams (I9 00:22:01). One participant explained the importance of forming these relationships, saying,

I think palliative care - at least at [this acute care facility] - we don't work well unless we're team members. If we come in and disagree with everything the physician is doing with that

patient, or promote a direction of care that is not what the physician might be doing at that time - we're no use to them. We have to find some sort of medium ground. I mean there's lots of times we'll have conversations with physicians around here just saying, "we're wondering if this is actually the best way to go about it," or "how about this?" or "what do you think about that?" - to work so that you're showing respect for these physicians who are taking care [of the patients]. Because really, when you think about it - I've always equated myself sort of like a used car salesman - if I don't present myself properly, if I don't agree with the rest of the team, if the family are unhappy with what I'm saying because it contradicts everybody else, then what use am I? You're not going to buy my car. You're not going to want me in the room. [I'm] confusing [you]. [I'm] giving you moral distress [...]. So you have to be a team member - understand what's going on, whether [or not] you disagree with it. [...] Your job is symptom control, pain management, and somewhat the emotional support that families might need while they're going through this whole process. (I9 01:01:53)

As part of their effort to form a team for patient care, the consultation sub-team worked closely with social workers and spiritual care providers, particularly in situations where moral distress may have been present, such as with cardiology and neurology patients (I9 00:30:54). They also benefited from support from the Health Region's ethics team, one situation in particular highlights this:

I'm taking a look at a situation we had last month where a patient wanted to have their breathing apparatus removed, and we knew that as soon as we did that that she would pass away, and we had another service telling the family that this pneumonia was actually resolvable over a few days as long as she could just handle a couple rough days. That they would try to resolve this pneumonia. But the fact is that this lady has cancer - we can't take that away. So they were completely mixed up, this family, and asking us to make her stay on the BiPAP for two days. That's not possible and at that point in time with the fact that they've maybe [been] given a bit of misinformation - or maybe just a corner of the story - a piece of it - because that's what respiratory was looking at - the infection itself. Then I feel that this becomes an ethical issue because at this point the family don't understand that there's a bigger picture and that the information that they have gotten is only a piece of it. It's not really an ethical question, but [the Health Region's ethics team that is available for consultation] can help us sort of figure out - suggest - who to listen to, I guess. (I9 00:52:40)

In addition to forming teams to improve patient care, palliative team members did their best to maintain good working relationships with other teams to ensure these teams felt comfortable asking for consultations (I9 01:03:55). Even during challenging situations, team member tried to



work with other healthcare professionals to provide holistic care to patients and families (I5 00:19:48). As noted by team members who had been with palliative care for several years, relationships with acute care teams became easier to form as palliative care incorporated more acute care services and provided more consultations for acute care patients, working alongside other teams in the hospital:

I think the entire health region has become a culture of more technology than it was years ago and that's changed the philosophy of our care of patients. It's also made us a little more accessible to the medical and surgical teams. If we're willing to accept patients who are not completely end of life - but sort of amalgamate ourselves or mix ourselves in with the medical and surgical teams - then we become part of their teams as well. And it's a much more inviting situation and they're much more willing to ask for our service. (I9 00:08:48)

Consultation sub-team members also stressed that working with teams outside the palliative care unit allowed them to avoid overcapacity and to reach more patients who were in need of symptom management, particularly those with chronic illnesses who may frequently shift between good and bad extremes (I9 00:31:54). Although some physicians resisted working with the palliative care consultation sub-team, the team credited their success with their abilities to maintain healthy relationships with most other care teams (I9 00:25:07).

When discussing the palliative care team's collaborative approach, participants felt that the palliative care team benefited from its small size, which made it easier to connect with various team members (I3 00:50:45; I11 00:35:43). This prompted one team member to comment: "as we grow, we want to make sure we remain cozy and that we remain attached to patients" (I12 01:21:57). Although the palliative care team had managed to function well with team members while reporting to different managers, many participants reported wanting to shift their structure to that of a more unified group under one manager (FG I12 00:09:19). It was hoped that such a structure would make it easier to build relationships with patients, as one participant explained:

I've been involved in [the palliative care program in another city] on a personal level and it was nice - it's nice for families that as they move through the system they don't have to, for example, tell ten different social workers their story. And that's how our system is now - that if they're at [one acute care hospital] they tell this social worker. If they're at [another acute care hospital] they tell that social worker up on seventh, and then they come to the unit and then they tell this social worker, and then they go home and tell another one. Whereas in [another city] you get one social worker and she follows you whether you're at [one hospital, or another, or in homecare] - wherever you are - and knows your story, knows your history, knows what all you've been through. And same with the physiotherapist and the occupational therapist. It's the same one. (FG I3 00:09:30)

The palliative care team's cohesion was strengthened by their conscious effort to encourage communication and team building, as well as by the team's organizational structure and size. The team was also greatly impacted by its individual team members; this will be addressed in the following subsection.

### **Attributes of Team Members**

Perhaps the greatest asset of the palliative care team was its individual members. Palliative care team members supported the popular belief that palliative care attracts a certain "kind of person" (I6 00:35:43), with several participants relating that they were drawn to palliative care through an attraction to the type of team members they found there (I11 00:06:03; I12 00:26:53). During their interviews and their focus group, the palliative care team members implicitly revealed their own characteristics and explicitly identified the characteristics of their colleagues. Although team members were by no means uniform, it seemed they might all be credited with excellent technical and interpersonal skills as well as a self-awareness that was sometimes lacking in other areas of healthcare. This section presents an outline of the characteristics shared by most team members, concluding with a description of the team's physicians.

Palliative care members brought with them a set of attributes that made them uniquely suited to palliative care. Many team members stated that palliative care was a natural fit (I1

00:25:31; I7 00:26:10; I9 00:03:54; I11 00:10:09), as was illustrated by one team member's experience joining the team:

I think I was pretty nervous at the very beginning about being on palliative care. It is definitely not an easy place to work. But I have found in my three or four years of working so far that a lot of my strengths and gifts are working with populations that are going through such intense life transitions and changes. And so I've really grown to love it, and love being part of the palliative care team. (I8 00:07:55)

One participant stated that she felt drawn to palliative care because it presented “very interesting work and very different work” that stretches her “skills in all different directions” (I6 00:03:07), while a colleague shared that she enjoyed the variety of challenges presented to her in palliative care (I9 00:00:18). While participants praised their colleagues' technical knowledge and skills (I9 01:00:00; I10 00:39:18), their primary focus was on team members' interpersonal skills (I8 00:03:51; I9 00:42:06). In addition to being described as welcoming (I1 00:56:36) and caring (I6 00:36:04), team members were also singled-out for their listening skills. One participant described her colleagues saying,

I think that there's so many different personalities on the palliative care unit. [.....] [They are] people who are very good at listening. That's a big one. [.....] There has to be [a] willingness to allow patients and families to go through what they're going through, and being okay with decisions that are being made even though it might go against what their views and values [are]. I think just kind people, patient people. I think there's just so many different personalities that it draws on. (I8 00:29:12)

A member of the consultation sub-team also felt that much of the palliative care team's success came from their ability to serve as leaders:

I've learned throughout working here that our job isn't so much about taking care of *a* patient and making sure all their needs are taken care of, but leading your team into the right direction and allowing them to make positive decisions on the care. I'm only one person. (I9 01:11:10)

These interpersonal skills were on display in the stories related by palliative care team, as may be seen throughout this chapter, and many team members shared that their job satisfaction came

from being able to help other people (I1 00:02:14; I3 00:06:22; I6 00:03:14; I11 00:10:09; I12 01:22:38).

Participants identified both themselves and their colleagues as persons of integrity who bring their whole selves to their work (FG I6 00:31:52; FG I12 00:34:13). One participant stated:

I don't feel I can split off who I am from what I do. I know there's a debate about that even in the political realm. Can who you are be totally, radically different than the role that you fulfill? I don't believe you can. I think you're one in the same. So if this is a mess on a personal integrity level, probably this is going to be a mess on a public, professional level. (I12 00:15:51)

Participants also shared that their commitment to personal integrity influenced their commitment to their patients:

[Who you are at work] has to be who you are, through and through [...] [For example], we have a memory tree that we set out at Christmas time. It's in the mall, and we've always done it on work time. And it's never been a big deal, but we're so busy now. So I went to my boss to make sure that she knew we were doing it on work time and she said, "did you always do this?" And I said, "Yes, we have - ever since I've been in there we've done it." "Okay," she said, "just work your hours as good as you can." But for me, I'm a kind of person that I always want to be upfront if I possibly can be because I don't want, three months from now, - this is small example - but her to come back and say, "why didn't you tell me you were using all these work hours for memory tree?" I want it on the table, so my conscience is clear. I know that's not to do with patients, but that's who I am, so when I come to work - if that was my mother or father, I want to have done the best job I can do for them. Not necessarily, "will it be what my mother or father would have chosen?" but I want to honour their wishes as best as I can. (I7 00:49:09)

In addition to wanting to live as persons of integrity, palliative care team members also had a profound commitment to their work (I7 00:39:11; I11 00:47:09). One team member identified the palliative care nursing staff as being "the ones that give and give and give and give" (I12 01:23:32), while another team member praised her colleagues, saying,

They're very committed. The one nurse - she's a senior nurse - and she had to go and start butterflies - for injectable drugs - and it's 3:30 when she gets back in the office, and she says, "I'll be doing it on my way home. I can't find my supervisor to okay overtime," she said, "you know what? It makes no difference, I'm going anyway." And the supervisor said, "yes, of course I'll authorize that." But she would have gone anyway and done it. (I7 00:42:46)

This commitment also expressed itself in the conscientiousness with which team members approach their work (I11 00:41:57; I11 00:59:59). One team member explained that she was attracted to the team “because everybody [cares] about what they do. No one ever leaves stuff for the next person, and no one ever leaves this patient in a mess” (I6 00:36:04). Another team member related:

I do believe that everyone on the team has a sense of trying to struggle with doing the best possible, so that there's no question in my mind that if there was an issue or a concern that it would be done from a place of [...] good intentions [...] and wanting to see the person for who they are. (I2 00:47:22)

The palliative care team’s conscientious commitment to their work was both a product and a contributing factor to their collaborative team approach.

The team members’ conscientiousness was rooted in an awareness of the deeper motivations and attitudes of both their patients and themselves. For example, one participant related a particularly challenging situation:

There was one other lady, and she asked me awhile back if euthanasia could happen, and at that point I said, "no, it's not legal." Pursuing why and what she was going through, her thought was that she was going to try and spare her children anything more because she knew she was dying. She was going to try and spare her children. And she ended up on the palliative care unit and her children came to her - the families came to her - and she died a fairly comfortable death on the unit. Her intent was to save her children anguish, when in reality they needed the time to be with her and to face it. To take away that time from when she said it [to when she died] - if she would have made it happen - they needed this time in here. They desperately needed this time to be around her, [but] she was trying to be a mother [and] protect her children. I think once we talked through it, it didn't get brought up again. It helped me understand and think about more what her motive was. She wanted to protect her children from seeing her suffer, but that was part of what they needed to go through. (I11 00:50:36)

While this situation focused on understanding the patient’s perspective, many other team members related the benefits of their own self-awareness (I3 00:38:02; I8 00:35:58) or that of their colleagues (I2 00:47:22). One participant explained:

I think knowing where you yourself are at and knowing your belief system - and not putting that on your patient or fellow team member - but knowing that. And being aware of some of those things in your head [...] that maybe aren't so great - that maybe you know you are going to think that thought, or you know you're going to say, "oh gosh, not that again!" or "he's doing it again!" or whatever it is - but consciously setting it aside in your head and thinking, "okay, well that's okay. Let's set that aside and carry on with caring for that patient the best that you can no matter what. (I3 00:47:42)

In a similar vein, another participant related her own inner monologue when addressing challenging situations:

I like to ask myself - and I ask my coworkers and my manager - "is there something I should have done differently? Should we have done something differently?" And I think sometimes what we do in situations like that - even though you asked me am I the only one that goes into a situation like that - when it's something like that, we actually adjust that and maybe more than one nurse will go. So that we can have two different eyes [and] thoughts on what to do a situation like that because we were both feeling the same way - both nurses that were going in. But at least you're not doing it alone and at least [I know] it's not [just] me. And [I get] maybe a different angle or a different way of connecting with someone. (I11 00:30:02)

Focusing on her own intellectual interests, one participant related the benefits of self-awareness, sharing,

When I did my training and my masters [...] my case study was on cognitive behaviour but also on a relational model - a feminist model. So my thinking and my training [...] looks at who we are in relation to ourselves, in relation to our families and larger system. So, on a theoretical model I think that that's so important as well. As well as just something that feels like a good fit for the work that we do with people. I think if we miss knowing who we are in the work that we do, and if we miss knowing who individuals are other than their diagnosis, we do huge disservice to the people that we work with it. [...] My personal belief is that you cannot - I don't believe that anyone is totally neutral. I think that if you know yourself and you know how you are in relationship so that it's always to the benefit of the patient. So that when we're in relationship, the things we choose to share are things that maybe benefit the patient or the relationship, if that makes sense. It's not an inappropriate relationship. It's still a very professional relationship that is geared towards what is in the best interests of the patients or the families that we're working with. (FG I2 00:32:32)

This self-awareness enabled the palliative care team to acknowledge their patients' problems (I3 00:43:03), while continuing to provide compassionate non-judgmental care (I12 00:23:39).

When faced with challenging patients, particularly those with drug addictions, one participant

explained that the team's goal should be to "accept that this is who this person is, and try to approach it with non-judgemental care. Not keep a blind eye to it, because we need to make sure that everyone who cares for him is safe" (I2 00:31:58). Another participant articulated the challenge of balancing awareness of their patients with being non-judgmental, saying,

In one way, maybe, it does help that my antennae are up in some circumstances [...] For me I have to watch that I don't then mistrust everything, or don't believe anything that that person would say or do because you can go too far the other way. So making that balance and still feeling like you can provide care. Because that's the most important thing - no matter what I think or feel about my patients or families can I still provide really good care? And that's the most important thing. To me I think that that's what we work on all the time - because we all have our biases and our opinions [...] and we don't always agree with what our patients have done. Some people use alternate medicine instead of going traditional; some people might have trouble with that and think, "oh wow, you put yourself where you are." So, I - that's not me, I have other issues - but trying to still provide really good care no matter what your feelings or thoughts are [about] what that patient has done. (I3 00:41:13)

Self-awareness also enabled participants to know their own limits. For example, some team members spoke about the need to know when to lean on other team members for support when engaging challenging families (I11 00:48:57), while another mentioned that she continued to work on other wards because she needed a "mental break" from the emotional work of palliative care (I6 00:04:13). Another participant acknowledged that she had chosen to remain part of the team outside the palliative care unit because it was a more natural fit for her (I9 00:39:53). This self-awareness regarding their personal limitations was connected to participants understanding of their professional limitations as well as to the limitations of the team. One team member related a situation in which a family member prevented her from seeing a patient in his home, explaining:

That was extremely challenging. That was distressing, and I ended up - we managed to somehow get him into the hospital because I realized that they were really in a situation where [there] were two very distinct people that needed help. She [needed help], and he also did, and I couldn't do it. I couldn't because I had to value her opinion - I [couldn't] go in there and to him. Or I could, but I could only say certain things. It took me awhile to sort

of convince her that we needed to get him to the hospital, and then it took a team effort because it took more than one person - [not] just me. So I had to recognize [my] limitation in that area. (I11 00:18:41)

This same participant also shared the challenges of having family members push for answers that she could not give:

I'm not God - and I just don't always know all the answers. And they'll ask - people will ask, "how long does so-and-so have?" or "what do you think it's going to be?" I get asked that lots [...] - on a call I'll get asked that. "How long have I got?" And we don't know everything that's going on in the body - [...] when they become palliative, [people] aren't going back for the x-rays all the time; they're not going back for their blood work all the time. There's lots of unknowns. You can only look at symptoms and look at a [trajectory] of what people are doing and whatever angle of decline [they're on and] anticipate [how] it's going to be [...]. But it also can be just a sudden drop, too. [...*mild interruption*...] I try to give everybody the opportunity of: "it might go this way, [or] it might go this way, [or] it might go this way," and prepare them for every [situation] because I don't know what else - sometimes you just don't know. (I11 00:27:35)

The need to be aware of the team's limitations was particularly evident for the consultation services team, who considered their primary role to be listening and offering support (I9 00:50:21) without taking over responsibility for a patient's care (I9 00:17:50).

Palliative care team members also demonstrated a profound awareness of the need for self-care. One team member questioned, "If we're not even healthy ourselves, how can we be bringing value added care to the personhood of the individual that we're caring for?" (FG I12 01:10:28). Team members relied on a variety of personal coping mechanisms to help them process their experiences on palliative care including journaling (I12 00:50:36), time spent with their own family (I7 00:29:52; I11 00:35:43; I12 00:53:53), gardening (I9 00:37:00), and support from both past (I7 00:29:52) and present team members (I3 00:25:17). Many team members also identified their religious faith as a source of spiritual support (I1 00:33:23; I11 00:59:59; I12 00:53:53), with one participant sharing, "I get up every day and I ask for grace. I ask for good words. I ask for the ability to see suffering that's before me; so that the individual and their



family are heard and [.....] not treated as if their views are [unimportant]" (I12 00:23:39). This same participant related a turning point in her career where spiritual meditation played a significant role:

Somewhere partway through my [career], I decided to do the stairs as a fitness goal. Oncology is on the 6th floor, and the chapel is on the 4th. So especially when I was just starting - because if you come from the cancer centre you start at the basement - so you go to ground, 1, 2, 3, 4 - by the time I got to 4 I actually really needed a breather. So it was helpful to go and sit in the chapel and catch my breath. [I found my way to the chapel more regularly after first just stopping to catch my breath.] I found a rhythm of an envisioning exercise where I would have the coat that I'd put on at the beginning of the week and I would have a coat that I'd take off at the end of the week. I think I still do that - I don't do it as formally and as physically as I used to do when I was at the [cancer centre]. But there's a nice little quiet room just outside of our palliative care unit. There's a nice, sunlit space for First Nations people that often is not occupied and recently [it has been decided to keep it] unlocked. I find that just taking a bit of time to sit [helps me put on or put off the 'coat' of palliative care that I wear when doing this work]. (I12 00:50:36)

In addition to their care for themselves, many participants also highlighted the need to care for one another (I3 00:26:47; I12 00:53:53), which will be further addressed in the section on real relationships in the following chapter.

These coping mechanism were generally beneficial because they allowed team members to let go of control of a situation; something which most participants felt was a key part of both self-care (I12 00:53:53) and patient centered care (I6 00:41:15; I11 00:48:57). One participant explained:

Sometimes for me it's just recognizing what I have control over and what I don't have control over - having a sense of, "this is an individual's life," and to fully respect it - to know that I'm a small piece of this part, and to look at what we can do. So maybe that's another piece - that because there is so much, I feel, that we can offer to make things more comfortable, or to make the best possible experience at the end of life. There may be things we can't do, but there's always some pieces that we can do to enhance the care of patients or families. (I2 00:38:29)

Relinquishment of control was particularly important for members of the consultation sub-team (I5 00:38:02; I9 00:56:06; I10 00:27:00) and palliative homecare sub-team, both of which were not the most responsible healthcare professionals for their clients. One team member elaborated:

It is hard. It is hard, but again [...] the way I think about it, myself, is to try to do my best job getting the information I can to the patients and families. And ultimately this is their experience, not mine. And so if they want more investigations and more treatments that are causing suffering - absolutely that's hard to watch - but on some level they're choosing that for a reason because it meets some sort of need - usually a psychological need - [so] they would need to keep intervening and keep trying. Because that hope is still there. I think I sometimes need to force myself to remember it is about their choices and as long as I've done my job: supporting them in making those choices and informing them of the pros and cons, then it's out of my hands. (I10 00:25:51)

As important as it was for participants to know when to let go of control in a situation, they also related the importance of taking responsibility for the patients in their care (I10 00:44:39). Most team members spoke about the need to balance their sense of responsibility with letting go and allowing their patients to make decisions (I12 00:33:49). For example, one team member related the following experience:

The one situation I certainly felt like I was in a scenario where I really thought the family member wanted their parent dead. I was very uncomfortable with that. The talk was pretty open, and I [thought], "what do I do with this? I can't pretend I didn't hear it, and I'm not here 23 hours out of 24 hours of a day. I'm only here for 45 minutes to an hour a day [...]" So it was very distressing at that time and I remember thinking, "all I can do is express my concerns to the rest of the team." It worked out all right - in that situation. There's a lot of unknowns too because you just don't know [what] happens [in] 23 hours out of every day. (I11 00:50:36)

Balancing the letting go with assuming responsibility was particularly challenging for physicians, as one physician explained:

Ultimately though, we are the ones who put our names on the prescriptions or put our names on the orders, so we are responsible. That's the truth. But to think that we know everything, or that we have the best assessment skills is short-sighted and limited. (I10 00:39:18)

Another physician gave an example of a particularly challenging situation:

Yes. One of the things that can come up is this whole idea of terminal sedation. It's when people are right at the end of life, and either they're in intractable existential pain or more often intractable physical pain or terrible shortness of breath or something like that. The one case that comes to my mind - [...] this was years ago - this was one of the hardest cases I've ever dealt with - somebody might have mentioned this to you. It was a middle aged woman, she had end stage [...] cancer. And she had some pain that was relatively well controlled. She actually seemed to be doing okay, but her husband wanted her to be sedated - terminally sedated. And [he] was very insistent - very, very insistent that she should have it. But the thing is, she wasn't close to the end of life. So we refused, and he became more and more insistent. [...] So she started on a low dose of a sedative, but we said [that] ethically we just couldn't sedate her. And he actually became so furious at us that he took her to a centre in [another province] - where they absolutely categorically refused to sedate her and she lived for several more months. It was horrible - I remember going in in the mornings and: "Well, I wonder how miserable he's going to be today." But sometimes it just has to be - in this case, it's "my way or the high way" literally, because I'm responsible. I'm the one who writes the orders. And terminal sedation is a touchy issue because you could be accused - I mean, people don't eat or drink - so you could be accused of [killing them]. (I5 00:39:56)

When balancing their responsibilities with the need to let go of control, team members also spoke about the need to find common ground and compromise (I9 00:33:54), pointing to their skills as mediators, which was discussed in the section on clear communication.

Although the palliative care team shared the care of patients, their physicians remained responsible for all medical decisions. The team overwhelmingly expressed great appreciation for the leadership of their physicians (I6 00:45:45), drawing particular attention to the physicians' knowledge (I3 00:50:45), compassion (I11 00:38:52), communication skills (I3 00:44:12), and commitment to patients (I2 00:41:46; I7 00:36:01). One participant elaborated,

I mean our physicians - and again, maybe we're fortunate in the numbers that we have - but our physicians track stuff down. It's amazing to me the stuff that's left undone with patients that come to us. Families will say, "you know, my dad had a CT scan 2-3 weeks ago [...] - we never ever heard what the result of that scan was," or, "Dad had a biopsy 3 months ago. Nobody's ever told us the result of that biopsy." Our doctors are constantly trying to get the whole picture of what's happening to our patients. And I think in the long run that saves time - and could maybe even save money! So if you know they had a CT two weeks ago, well track it down! Don't repeat the CT - it's not going to show anything different in two weeks. And yeah, it takes a few minutes to track that CT down, but it probably takes less time than you ordering another one. So, just that ability of trying to get all the pieces of the [puzzle] in order so you know what's happened with the patient. It just makes such a huge

difference to know that, "well yeah, no they can't have anymore radiation," or, "the cancer clinic isn't prepared to offer anymore chemo." So don't even phone and ask them - you already found that out, because you phoned and got the record from there. So lots of things that are followed up by our physicians and our team, that just never gets done out in the rest of the hospital. (I3 00:50:45)

As discussed in the section on clear communication, team members also praised their physicians for their approachability (I3 00:50:45; I7 00:47:23; I9 00:16:33), their willingness to be available on-call (I11 00:47:23), and their openness to suggestions from other team members (I2 00:20:21; I6 00:46:22; I7 00:46:00).

In addition to their communication skills, palliative care physicians bring a number of other assets to their team. The participating physicians described palliative care as a natural fit for their skill sets (I5 00:10:19; I10 00:04:01; I12 00:06:26). They reported that their communication and interpersonal skills were especially beneficial in palliative care (I5 00:54:27; I10 00:22:32; I12 00:02:47), and that they felt particularly drawn by the opportunity to work as part of a team providing holistic care (I12 00:29:31). By their own account the palliative care physicians valued feedback from their team members:

Absolutely. And I think because we have to deal with things holistically, there's no one member of the team that can work alone. And I think that makes us quite different. When I look at some of my medical colleagues, I notice that [...] they rely on their nurses as much, but I think we really could not do what we do without our nurses - nurse coordinators, social workers, therapists - all of it! I think they become a more key part of the team in palliative care than maybe they are in other [units]. Or at least us as physicians appreciate them as part of the team. (I10 00:09:40)

Along with their leadership in patient care (I9 00:39:10), the physicians also took a leadership role in ensuring team cohesion by making an effort to encourage dialogue (I12 00:56:06), organize team social events (I7 00:46:00), treat staff respectfully (I11 00:38:52), and support individual staff members in times of distress (I3 00:50:45; I7 00:41:01; I12 00:50:36). One physician expressed her concern for her team members, saying,

In the last year I'd say I've had distress just watching one of our team members who I think has gotten really significantly burnt out. And then trying to figure out how to call them back - how to encourage them to start doing some self-care. (I12 00:53:53)

These skills helped the physicians to develop a strong team around them and to foster the multiple viewpoints that were deemed necessary to provide holistic care.

In their interviews, it became clear that the palliative care physicians shared a common devotion to holistic care (I5 00:51:38; I10 00:09:40; I12 00:58:40) and were not territorial in their team approach to their caseload (I5 00:07:11). One non-physician team member explained her view of the physicians' patient centered care, saying,

Well I think they have the ability - and maybe it's part of what they like doing - of looking at the whole patient. So they don't just look at their cancer, they look at the whole patient. So they look at the fact that, "gee, their wife just died 3 months ago, so they're still grieving over that loss and so are their children." Or, "they live in a basement suit and they can't walk down the stairs." I mean the doctor often thinks of that - it's not just the therapist. So they think of the whole patient, or they think about the fact that they're estranged from their children and so what does that mean? They're just so astute at looking at the patient as a whole, not just at their symptom or whatever it is that they're doing. And the value of that teamwork, and that everybody's input is just as important as theirs. (I3 00:54:58)

Another team member echoed these observations, explaining,

What I have noticed is when any of this team [realizes that patients and families have questions], the doctors really do try to make a special point of creating some extra space to make sure that families do have a chance to express what their concerns are and their fears, or their questions. (I2 00:12:57)

Much of the physicians' success as providers of holistic care was developed through their clear communication skills. The physicians also made an effort to facilitate difficult conversations (I2 00:34:43), as one physician explained,

I don't know that it gets explained very often in terms of how we interact with a patient. We do make it clear - for example, if we're transferring someone to the palliative care unit - that we don't do a lot of investigations or vital signs or those sorts of things. So those active - what the patient would experience - is quite different. But I think even on the consult service at [an acute care facility] for example, when we go see a patient who is used to dealing with surgical teams - I think they can tell that we have a different way. Often times we'll go in a room and sit down and spend time with a patient, hearing about

their life and what's happening for them. I'm not saying that my other colleagues don't do that, but internal medicine doctors who have a roster of 30, they just don't have the time to do that. So I think [patients] perceive quite quickly that we have a different focus. I think it's subtle. It's not necessarily that we'll walk in and say, "okay, we care about your experience and your family. Please tell me about that." (I10 00:12:36)

The physicians described speaking with patients about challenging subjects as a “delicate art” (I12 1:06:26), while their team members also emphasized the physicians’ holistic approaches to care, with one participant observing:

I've never heard a physician say, "well, you're not experiencing pain." What the person says is their experience is taken, and so that team includes the patients and their families. There's a lot of time spent on having conversations and encouraging dialogue and communication, and questions. Families are encouraged to ask questions and the team is very good at - especially our physicians - at taking very complex medical situations and distilling them into a language that is accessible and [understandable] and not clinical, necessarily; not dumbing it down and not trying to protect individuals or families from knowledge, but spending the time to talk about it and discuss it in a way that makes it understandable. (I2 00:04:11)

Although clear communication skills and a focus on a collaborative team approach to holistic were prevalent in palliative care physicians, participants felt that the palliative care skillsets were by no means exclusive to this group of physicians and thought that these could be adopted by anyone (I9 01:00:00).

### **Benefits of a Collaborative Team Approach**

Palliative care team members took great pride in their team, and credited many of their successes to their collaborative teamwork. One team member stressed that the team members “very much love what we do and [are] very proud to work with the people that we worked with” (FG I2 01:10:08), while another explained:

I think what we do so well is that people come to the unit maybe expecting to die, or [they're] just scared to come to the palliative care unit. And I really have to say that I'm so honoured to be part of [a] team that really does make people feel as comfortable as possible in the circumstances - to really hear where they are at. And what's interesting is that often times you hear about patients improving in health even though they came to the

unit in such distress. It's amazing that people just all of a sudden become more coherent, more clear, [their] pain is better controlled. (I8 00:54:41)

These improvements in their patients' conditions were largely credited to the team's commitment to holistic care (I9 00:09:40) and, as noted above, their ability to see a patient from multiple perspectives when they work as a team (I11 00:18:41). The benefits of a team approach to holistic care extend beyond the palliative care team to the teams with whom they worked (I9 00:00:18; I11 00:26:12; I11 01:08:56), particularly through the Pain and Symptom Management Clinic which bridged care between the palliative care team and the cancer clinic (I11 00:22:47).

A collaborative team approach benefited not only patients and families but also the team members themselves. One participant stated that the team has a responsibility to "stay healthy" and that to stay healthy they needed to be able to provide each other with feedback and support (I3 00:49:06). Another team member extolled the benefits of the team approach, saying,

I think that when you're part of a team you can do better work. You can do your best work when you are a part of a team. You're better informed. You have support. There's a chance for you to teach others too. I think there's just so much room for growth. (I8 00:59:52)

The well-functioning of the team also allowed team members to help patients to avoid undesirable outcomes (I7 00:36:01) and to find creative solutions to achieve patient goals. One participant outlined the benefits of the collaborative team approach, saying,

I feel like I have some support behind me - I don't always have to have all the answers. I can call on team members; I can call on doctors. I can [say], "I don't know. I'll go back and check with my colleagues and I'll call you back today if I don't know what we should do here at this point." So I never feel alone, but I feel like I've got a team behind me that I can [use to] help people. I have a really good team behind me. A really good team. (I11 00:10:09)

Although these benefits were stated explicitly in this section, they may also be found riddled throughout the stories reported in this chapter.

Participants generally felt that a collaborative team approach was accessible to most other areas of healthcare. As one team member explained,

I think one of the things we do well in palliative care is - ideally - we work together as a team; we treat each other respectfully. If one of the nurses who is looking after a patient tells me they need something, I'm not going to question her because I trust that person's judgement - usually, I mean if someone really new suggests something outlandish I'm not going to agree. So I think that that would really make a difference in the healthcare system in general. It's so hierarchical, and I think that's one of the things in palliative care that we really do well. We work really well together. So the nurse that I work with - she calls me every day - sometimes she calls me five, ten times a day - "I think we should do this?" And I say, "good." (I5 01:04:24)

Other team members also criticized the hierarchical structure of many healthcare teams (I2 00:51:46), while another suggested that other teams would benefit from the services of nurse coordinators (I7 00:55:39). One team member further stated,

I believe [in] actually creating teams - and not necessarily interchangeable teams, but where you actually get to have some sort of relationship or connection with the team and trust with [the people] you work with. [...] And maybe it's different when people are doing surgery as well, because then they're in the O.R. and not as accessible, but I still think there's components of having a team that works closely with each other. (I2 00:49:44)

Participants also felt that healthcare team outside of palliative care might need encouragement to engage their patients in end-of-life conversations (I9 01:11:10), while another felt that, in general, healthcare professionals would benefit from learning to give up the perceived need to control the hospital environment and realizing that their job was to help their patients “function to the best of [their] ability, not to control everything [they do]” (I6 00:41:15).

The collaborative team approach used by palliative care team members relied heavily on the individuals who made up the team. This approach to patient-centred care drew on the team's clear communication skills and allowed the team to build relationships that formed the backbone of their exercise of holistic care.



## Theme C: Holistic Care

When asked to name the defining characteristics of palliative care, almost every team member interviewed mentioned the team's patient-centered approach to holistic care (I8 00:08:58). For example, one participant shared a story in which she felt she owed her success to her focus on holistic care:

[I was on call] - and this was a patient [at an acute care hospital] - he was on the team, but he wasn't on the [palliative care] unit. He was an older guy and he had been in the hospital just for a few days. He had gone downhill very rapidly and I got this urgent consult - I was just about to leave the hospital - I got this urgent consult to come and see this guy. And he was really deteriorating quickly - I could see that he was going to die. And I actually knew the daughter because she had been [at another hospital]. So here he was - he was laying there, and the doctor, the internist who I know, said, "I don't know what to do." She said, "I want to start him on a magnesium drip and I want to move him to obs - close observation - there are ten people in there, and curtains, and beeping monitors - very busy. It's kind of a step down from ICU. I said something like: "I'm not sure that's a good idea." I said, "I want to go talk to the family and see what their wishes would be. I don't know if they still want that kind of acute care, and I don't know if they know how sick he is." So I went back in and I talked to the wife and the two daughters and said, "you know, it looks to me like your dad is near death. What would your wishes be? The doctor in charge is thinking about moving him to observation and starting some new drugs. That would be one option - but the other option would be to move him into a palliative room and you could all just come and be with him. But we wouldn't be doing any really active treatment. What would your preference be?" They wanted to just be in a quiet room and not to have anymore treatment. And fortunately the doctor was okay with that. So he actually died three hours later. And that's the approach that we bring - otherwise he would have been moved and been in a really noisy space on a narrow bed with curtains on either side with no room for the family. (I5 00:19:48)

This participant also provided a more detailed explanation of her team's unique commitment to caring for the whole person, sharing,

There's an ethical lens that we use that I think is very different. There's a concentration on - ideally - the whole patient and the family. So when I go in to see somebody, I wouldn't just be looking at, "this is somebody with cancer, and how might I treat that?" [.....] Just today when I walked in to see that woman with cancer - the woman younger than me - just going in. And I think there's a different kind of lens that we use. And it would be a lens of: Where is this person physically? Where is this person? Where is the family? Where are they physically? Where are they

emotionally? Where are they spiritually? Where are they? You know, so her mother - was 84-85 - just seemed tight, very frail physically. [.....] So where is this family? Where are they all? And you can't know that - I can't know that - but I'm looking, and I'm trying to sense who's distressed here? It's not always the patient - they're not always the most distressed. I think in that situation, in that room it was the mother who was probably the most distressed. So how do we do all this? How do we look at that? (I5 00:51:38)

This commitment to understanding the whole patient, rather than just a disease or illness, was repeated throughout the interviews and focus group (I6 00:32:41), with one participant sharing that palliative care physicians,

Don't just look at their cancer, they look at the whole patient. So they look at the fact that, "gee, their wife just died 3 months ago, so they're still grieving over that loss and so are their children." Or, "they live in a basement suit and they can't walk down the stairs." I mean the doctor often thinks of that - it's not just the therapist. So they think of the whole patient, or they think about the fact that they're estranged from their children and so what does that mean? (I3 00:54:58)

Another participant succinctly stated that “none of us really aspire to be the pancreas in [room] 574” (FG I12 01:09:15), an observation that has informed her care for her patients. This section will explore the team’s approach to holistic, patient-centred care, as well as the goals and tools used by the palliative care team to achieve positive outcomes.

### **Patient-Centred Care**

The patient-centred approach to holistic care was generally described as “looking at people as a whole and [...] spending the time to get to what that individual’s experience is” (I2 00:04:11). One participant contrasted this with the approach used in other parts of the hospital, saying,

Often I think in other parts of the hospital they're looking at a specific part, like a broken leg - and maybe this is oversimplifying it - but a broken leg or surgery on a specific body part, right? So, the time isn't really spent to find out what they did for a living, who’s important to them, what are their belief systems? Are there things that are important for us to know so that we can provide that care for them? It's much more in and out and very task orientated. Where I work now, I greatly respect the other individuals on my team and how they value the psychosocial piece as well, so that even though each of us have jobs, there's

- I would say - an overlap, in some ways, of care for the psychosocial piece. So whether it's the person who's emptying the garbage or delivering the meals or giving the bath, there's an attention to finding out who people are and what their experiences are. (I2 00:04:11)

Another participant described her approach to patient care as “trying to meet the patient [...] where they're at.” She elaborated, saying,

If they still have a lot of hope for a cure, then I think it's important that we help the patient maintain a sense of hope. Because I think hope is important to the human experience. But we're trying to walk with the patient to realize that maybe the hope that they have is not going to be directed in a helpful way. Hope changes for our patients. Early on in a person's disease trajectory the hope might be for a cure, but later on hope becomes about comfort, or about spending the rest of their life either at home or in a [care home]. I think it's really important to figure out what is important to that patient, and how [you can] achieve that. As I'm thinking about this - again I'm not sure if this is a valid example, but this is where my brain went when we were talking about this: I met a patient this morning who was a bit confused and so she wasn't able to make her decisions. But the family helped us realize that what was important to her was going up north, to be in her community, to spend the last remaining days. So [we're] trying to figure out how to make that happen for her, but then it was interesting - as I was reviewing the chart - she has lung cancer and has chest pain issues. And a new resident on the team was thinking, “chest pain. Must be cardiac. I need to do a cardiac workup.” And so working with that family, trying to explain in a way that - first of all, it probably wasn't her heart - she has other reasons for pain in that area. But were the results of that cardiac workup actually going to help her with what was important to her, which was going home? Probably not. [It was] probably just going to slow the discharge down when they were really anxious to get her home as soon as possible. Again, it's important to figure out where that patient is at, and how do you help them achieve their goals? (I10 00:19:48)

Team members felt that listening to the patient's experience was key to providing holistic care (I8 00:10:48), with one participant stressing that the patient-centred approach recognized that “each individual is the expert on their own experience” (I2 00:04:11). Another participant explained that this is particularly true when dealing with pain management:

I think the biggest thing that we do differently is focusing on the patient's experience. Imaging reports or the lab results are important, but they're less important than what the patient actually describes - assuming they're able to describe it. We deal a lot with symptom management. So when you're dealing with something like pain control, it really comes back to the patient's experience of that pain. What is it to them? Is it a mild pain? Is it a severe pain? How does it affect their function? These are not things that can often be measured; it all comes back to the patient's experience. So we really take what the patient

says very seriously, and that's almost more important to us than the rest of it. (I10 00:08:17)

Participants also focused on the importance of providing patients with choice when providing patient-centred care (I10 00:25:51). One participant explained,

I think [palliative] care is just geared towards the patient and family so much more when palliative care is done well, and that the patient and family feel like they have so much more choice. Whereas in acute care medicine you really just get in a stream and the water or the current carries you along. With palliative care I think there's a stream, but - and some patients would like to stop the stream, would like to turn the disease backwards - but I think there's just so much more attention to: "what's the temperature that you'd like the water to be at? What's the confounding - or the eddies that are coming in at you, in terms of what you have to cope with at the same time? What unresolved turmoil is there that will prevent you from finishing well? And even just bringing patients and family to a point of some sort of acceptance that there is sometimes no cure for a particular illness. Palliative is a hard, hard label for some individuals to embrace. (I12 00:08:07)

Another participant described her role in patient care, sharing,

You know I really think my job - sometimes - is: "okay you've got limited time here. What would make you happy? What can we do? What's upsetting you? How can we fix it? Can we fix it within the realm of this place? Can we provide support so you don't feel like you fall off some sort of wall or cliff when you leave here?" And it's the best job - I mean as long as you're not taking a look at trying to fix your patient so they survive - this is a very enjoyable place to be, this position. (I9 01:07:06)

By centering their care on the patient, the palliative care staff felt that they were able to learn more about their patients' experiences and to focus on their needs, rather than just focusing on an illness or disease.

The palliative care team's commitment to holistic care extended beyond the patient to include his or her family as well (I11 01:06:46). The families' involvements were important, not only to provide staff with information concerning the patient's illness and health (I10 00:16:21), but also because families have a tremendous impact on the patients' healing (I11 00:55:30). One participant explained that the team included families in their care because they "realize that families are affected by the patient's journey as well and they are going to impact back on how the

patient receives things” (I10 00:08:17). Other participants echoed the impact of the patient’s journey on the family (I5 01:07:53; I12 01:04:09), with one expressing her hope that the care provided by the palliative care team would reduce the “chance of complex bereavement or ongoing health issues” (I2 00:17:46). Another participant stressed her concern for the patient’s family, stating,

I think the client is number one. But the caregivers around them - and I always say [of] the caregiver -I need to take care of them too. Because if the caregivers - and this is in the home setting - if they burn out, and then they get sick, then we've got two people in the hospital. We've got no choices here. Our goal - I always say, "our goal is to keep you out of the hospital" - that's our goal. Most people don't want to go to the hospital! They don't want to go - they really avoid that if they absolutely could and that's our goal too - is to keep you out if we can. Unless you have to go. (I11 00:58:52)

The team also described the negative experiences of family members who spent lengthy periods of time with their loved ones in the healthcare system and stressed the need to ensure that families felt valued (I12 00:23:39). One participant shared her approach to families and their role in providing patient care, stating:

I do think that we certainly value the patient and their family's input - it's huge! We tell the family all the time, "you are part of this team." We tell the patients that all the time, that, "only you know what you're experiencing. You know when you're having pain. What's your pain like?" So, we very much rely on the patient to tell us, "this isn't working," or, "this is better," or, "no I don't like that." We very much rely on the family to help us far as history goes, to say, "no, they tried that drug before, and here's what happened." Or often times they'll see changes in their loved one before we will because they know them so well. So they'll say, "well no, Dad never was like that ever before and now he's saying strange things." And we might not even catch it because there may be things that aren't that obvious to people, but they're little tiny things that only the family will know. So we very much value their input and I think that makes a huge difference in how their care's managed and how they progress. Which is kind of a funny word to use in palliative care! But progression to me is that they're feeling as good as they can feel given the illness that they have. (I3 00:13:32)

Although most team members used the phrase ‘patient-centred care,’ it was clear from their interviews and the focus group that their real focus was on ‘patient-and-family-centred care.’

In their reflection on holistic approach to care, several participants emphasized that palliative care was process-oriented rather than goal-oriented (FG I6 00:46:14). One participant stressed that this stemmed from the patient-centred approach to care, explaining,

I think we try and match pace with patients and families a little differently than some other wards as well. [The attitude on other wards is]: "This is the pace; pick it up; get in the queue." On other - recuperative - wards, it's much more: "Get with the program." Whereas our team tends to be: "What's your program going to be?" Because we are dealing with they dying, so it just is different. (FG I12 00:45:43)

Another participant described the difference between palliative care and other units of the hospital, saying,

The pace is different. The feeling when you go on to palliative care - it doesn't feel like the other wards. I've worked in emerg, I've worked on 7, I've worked on 6th, I've worked in ICU, I've even worked on 5b. And a lot of the other wards are like hustle bustle, everybody is in such a hurry - it's like push, push, push, push, get things done, get things done, like they don't have time. It's not that they don't care! It's that they don't have the time, they don't have the staff, they don't have anything. (I1 00:35:58)

Being process-oriented was important for team members working in the community as well. In contrast to district homecare nurses who tended to be task-oriented (I7 00:06:41), palliative homecare nurses felt they were able to spend more time with patients, as one participant related:

I think one other thing we sometimes do too is we don't just see people when they're in crisis and say, "well if you're fine today we won't bother coming to see you." We still try [to] go out and visit the family and connect - because there's always support we can [give], even if there's nothing - no pain or no nothing going on, they're symptom free, so to speak - we still like to visit with them because - for that reason - there's a support there, there's that understanding that we care and that they know that we're not just there because they're sick. We're there because we want to be there for them - visit with them, connect with them, find out more about them - in a healthier situation. Those aren't wasted visits. That's [a former homecare nurse]'s talk. That's what she said: those people - keep them comfortable and settled and maybe out of the ER - because they're feeling supported - then those are valuable visits. (FG I11 00:55:42)

Although it might be challenging to adapt to a patient's goals, team members related the importance of focusing on one day at a time (I6 00:41:47), being flexible (I10 00:15:14) and

patient (I7 00:16:39; I9 00:28:20; I11 01:02:50) with patients. One participant felt this was particularly true as patients adjusted to being near the end of life, sharing,

We had a couple really long talks with [one patient] about [her prognosis] - she just didn't believe. But the time came - it was probably a couple of weeks later - that she somehow realized that she was not getting better. In fact, she was getting more and more ill. It seems, for some people they really need time to absorb the diagnosis and how sick they are, and she really needed that. She needed a few weeks. And the time came that she realized - and her husband realized - that it was time for her to move to the palliative care unit. (I5 00:15:44)

Palliative care team members also felt there was great value in meeting patients early in their illness to help the patient adapt to the pace of palliative care. One participant explained,

I think it's better now because for the last year and a half to two years we've had a presence at the cancer clinic. Before that we didn't have any palliative care representation. Patients when they met palliative care, [it] was like, "well there's nothing else to treat you with so now we'll send you to the palliative team." And now it's much more: "we'll walk alongside - palliative and [disease-modifying] care. And at some point the [disease-modifying] care will drop away but the palliative care will continue." I think that when patients used to have the hot potato/cold potato experience, there was a lot more fear because when acute interventional treatments were [finished] according to the oncologist - sometimes according to the patient or family - but most often the oncologist said, "there's really no point in continuing on this treatment" - that just left patients so fearful of what was to be. And they didn't know us yet. So then they have to meet a new team at the point where they're most vulnerable. I mean - would there be an individual that would comes to mind? Every single person who comes onto the palliative unit - even if they're followed by our counterpoints in the community - it's such a fearful experience. What will this be like? And within 24 to 48 hours there's such a deep breath that comes, and when patients come from other places in the hospital there's such a sense of, "oh, yes. This is what medicine should be like." (I12 00:09:38)

This process-oriented care was enhanced by both the team's access to physical space and the extra attention the team gave to the psychosocial dimension of care. As mentioned in the section on clear communication, many team members valued the physical space present on palliative care because this space allowed more opportunities for patients, families and team members to interact (I2 00:23:42; I3 00:50:45) and gave patients more "ownership of their

space” (I8 00:42:28). This was particularly important given the holistic approach of palliative care as it provided more room for families, as one participant explained,

The rest of the hospital is not designed for families to be [together or sometimes even] comfortable. And we certainly in our country do not provide for large First Nations families to come and be as they are in all other ways. And in fact we kind of get miffed - or staff get upset - because [sometimes there are] so many people here. [...] And that's a barrier to people coming into hospital or hospice - is whether there's space. So I think [...] if you're having your gallbladder out, you don't need lots of space. You don't need fourteen people with you. But actually, if you're end stage heart disease and this is your fourth MI, and the docs really aren't sure whether the medicines are going to turn things around this time - an observation unit with a curtain and one chair when your family is six people, is rather poor. So when they come to our unit, it's like there's room to breathe here, there's room for a bed to be folded out. [...] Four bed patient care rooms are only good for observation units. It's only good for us as medical staff - it's terrible for families. (I12 01:01:00)

The extra physical space on the Unit was perceived as beneficial, but the team stressed that the ability to create the emotional space and time needed to process the challenges of life limiting illnesses was significantly more important (FG I2 01:01:20) because, as one participant stated, “it creates space for the unseen; for things to bubble up; what might be underneath?” (FG I2 00:56:46). Another participant explained that for the consultation sub-team,

It's not so much the physical space to me, it's encouraging staff members to be able to have [conversations about the end of life] in the right moments. Community nurses come out to the home and they're able to have those conversations because they're in the patient's home - the patient [feels] comfortable. Here it's a matter of: the hospital bed, and the patient's room, and my presence are foreign to these people. I'm not there very long - I'm there for half an hour, maybe at the most. My idea would be to be able to encourage staff members [to] have those conversations themselves. We're not able to take over here. (I9 01:11:10)

Team members stressed that communication skills, collaboration (I2 00:31:58) and having routine moments to discuss issues such as advance care planning (I11 00:43:42; I12 01:17:48) helped the team to holistically address end-of-life concerns. As one participant phrased it,

My job is to make sure everybody's comfortable with having those conversations. And that we're all on the same page. It doesn't matter who does it. If it's the nurse that's on there for twelve hours and the patient feels so comfortable - I [saw] that the other day. That's the



perfect opportunity - not necessarily when I walk in with my briefcase for five minutes. (I9 01:12:20)

The team was praised by one participant for making an effort “to give space for what patients' or families' experiences are, and not trying to convince them of something different” (I2 00:08:01).

This participant further elaborated:

Family members do have experiences where they've felt that people haven't told them what's happening or they haven't been able to access, or they have questions about things not being caught soon enough. What I have noticed is when any of this team picks up on that piece, the doctors really do try to make a special point of creating some extra space to make sure that families do have a chance to express what their concerns are and their fears, or their questions. (I2 00:12:57)

Giving patients the space needed to process their situation was particularly important if the team found themselves in disagreement with a patient, as one team member shared,

I think if I felt [a situation] escalating and I couldn't defuse it on my own, honestly I think I would just tactfully walk away. I think there is [...] a time to say, "I feel like we're not getting anywhere with this conversation. I'd really like to revisit it, but I'm going to come back tomorrow," or, "I'm going to come back this afternoon and we can talk about it a little bit more." Because really, escalating it or allowing it to escalate doesn't help the patient. Because again, it's usually the person who's lying in the bed - who's unwell, vulnerable - they don't want anybody fighting. I can remember a few situations where I've had to do that, and usually by the time we both cool down and come back, it's easier to talk about the issues. Plus it gives the family a time to connect [about] what they want more. (I10 00:31:11)

Participants also stressed that creating this space needed for holistic care required time (I2 00:23:42; I3 00:06:22; I10 00:24:05). As one team member shared,

I don't look at the clock the same way when I go to a client's home, and I try to give people the time they need. I'm not just dealing with a wound, or I'm not just dealing with a med that I need to give and then leave again. I've got to look at a whole picture. I might [go to a home] and think, "they've been doing really well; this probably won't be a long visit," and walk in and [think], "nope. Something has changed. I need to slow down here, and I need to give them more time, and I need to help them get through this next part or find out [what else there is to do]." (I11 00:11:57)

Another participant focused on the time it takes for careful observation:

It comes down to just talking [with families] about things, and just trying to explain what we as clinicians are seeing and what's happening. Sometimes that takes time, as well. Because you can say, "yesterday I noticed this about your mom, and today I'm seeing this." So that change with time is really valuable because most of the time patients and families are seeing the same things you are, they just need to have it clarified that, "yes, this is what it means." (I10 00:30:23)

These sentiments were echoed by another participant, who stated,

As a special care aid, as a registered nurse, as a doctor - when you watch the patient, you see stuff that shouldn't be, or that is getting worse, or is getting better. And then that tweaks your assessment skills right there. And then you're able to say, hey, that wasn't there yesterday, or that's worse than yesterday, or that's worse than last week. (I1 01:05:32)

Although the palliative care team benefited from a lower patient-to-staff ratio than other areas of the hospital (I6 00:06:16; I9 00:29:34; I10 00:28:32), it can still be challenging to find the time needed to create space for holistic care (I9 00:15:07). When asked how the palliative care team was able to find this time, one participant stated,

You just do it. Like I never take coffee breaks - sometimes my dinner is chucking the food in my mouth! But you know that if you're in a situation where the family is about ready to open up, the worst thing you can do is walk away. If this is the moment that they have that they need to talk - and if you're there - that time is precious to them. It's not like somebody's going to recover here. So you just make it work. (I9 00:28:55)

Team members seemed to genuinely value the time they were able to spend with patients and families (I12 00:46:12), with one participant observing,

I think sometimes you look and you think, "geez, you spent 45 minutes with that patient. How can you - that's too long in a day! How do you get other things accomplished?" And maybe it is long, but on the other hand if you're just looking at time saving [...] then you might have actually saved time in the long run because you've spent that extra time with the patient and family and they feel like their input is valued and they feel like they matter. So, down the road who knows what good may come out of that interaction and that care. And then I think they do feel like, "yeah, they're on my team, they're [...] trying to help me out here. (I3 00:15:06)

Time became important not only to help patients and families to process their concerns, but also as a valuable resource to help team members to establish relationships with the people in their care, as will be discussed in the section on real relationships in the following chapter.

## **The Goals and Tools of Palliative Care**

The team's focus on patient-centred care and commitment to creating space for end-of-life conversations stemmed from the goals of palliative care. One participant described the goal of palliative care, saying,

[Palliative care is] working with individuals who have a terminal or life threatening illness. Symptom management can go from anything from physical pain to symptoms like nausea or constipation to emotional distress. So I work with patients to try to increase their quality of life, not necessarily at the very end but when they have a disease that's defined as life threatening or terminal. We work a lot with pharmaceuticals for pain management, but also [with] adjuvants to help with symptom management. On the other side, [...] [our] idea of being able to listen and communicate with [our] patient is very import to us because otherwise we don't find out what's important to that patient and sometimes we can facilitate - with the other team members - a whole care that takes in that whole person - or that idea of holistic suffering.

While several team members shared a similar articulation of the goals of palliative care, various participants also expanded on their objectives. One participant focused on palliative care's less interventive approach, stating:

We ask the question: do we need this? Is this helpful? What does this patient need? What does this family need? And not so much what do I think they need, but what do they think they need at this time. And it isn't [that you] go in with blazing guns and whatever else; "I'm going to save you!" It's not like that; that isn't what we do. So we go in as a team and hopefully connect with [the] patient and family and work together to decide what may be helpful. (I5 00:11:35)

On a different note, another participant summarized the goal of palliative homecare saying,

Our goal - I always say, "our goal is to keep you out of the hospital" - that's our goal. Most people don't want to go to the hospital! They don't want to go - they really avoid that if they absolutely could and that's our goal too - is to keep you out if we can. Unless you have to go. (I11 00:58:52)

Participants also articulated a deeper calling in their care for patients, as one team member explained:

In fact we're often trying to help people realize that their worth is not their doing. When they can't physically get with the program, their value is still as intact as it would be if they were up and mobilizing and doing other things. (FG I12 00:46:25)

Another participant expressed a similar opinion about the goals of palliative care, stating:

There's a different focus when you realize that you don't necessarily have to fix what's happening, but [rather you need to] be with the patient through it. It's a different approach and it's a bit more heart centered. It's still medicine - you still have to bring your brain too, but it's different - the way you approach those patients is different than I think my surgical or internal medicine colleagues do. (I10 00:05:14)

One participant highlighted the uniqueness of this approach to care, explaining,

[On] all the other wards they're doing everything medically possible for this person [...] but then you come to palliative care, especially those on care at the end of life. I find peace in the dying - there is peace in dying because they're done. They're done with the tests. They're done with the heroic measures. They're done with the cancer treatments. They're done with the dialysis. They're done! In palliative care the focus is different. (I1 00:35:58)

Several team members explained that in order to reach their goal of managing their patients' symptoms, the care they provided must be patient-centred. As one team member explained:

You have to go where that person is. So, to create a care plan and an agenda is not patient-centred. So, it's important to know not only what our goals of care are, but most importantly what is the patient's. When they were admitted, what are the issues that were of most concern to them. And to check to see: Do we know what their goals of being admitted are? What are their concerns or their worries? And what are staff's? I think that is a huge piece, so making sure that that has some reflection is important. (I2 00:33:42)

This participant also shared the process behind setting goals with patients, stating,

I would say that it is very much an ongoing assessment, and it's always being fine-tuned and revaluated, and there's a continuous circle. In many ways it would be very much a feminist assessment, where it's never completely finished or completely flat; it's almost like a living document - but not so much a document, but a living piece where there's always that conversation between the team but also with the family. (I2 00:25:43)

While the team was clearly patient-centred, they were also aware that the goals of care must be realistic to have any value. One team member explained her thought process when approaching the goals of care, sharing,

Sometimes I think when people have struggled with addictions or their life has been chaos for the majority of their life, that perhaps it's unrealistic to expect that the end of your life is going to be this amazing, peaceful, quiet - I'm not sure I like the term "good death" because sometimes I think it has a picture associated with it. Sometimes for me the

struggle is, what is good enough? What is the good enough care? Or what do we need to do to get it to a space where the most has been done that can be done? It may not be with all the - as neat and as tidy and as pretty as we might like - but what is good enough? How do we know that we've done the absolute best that we can? (I2 00:28:29)

Another participant felt that a holistic approach to patient care helped healthcare professionals to uncover more realistic goals for patients. She shared one story in particular:

I saw a woman today - they live on an acreage, she's a fairly young woman - so is it realistic that she could go home? What are we aiming towards? That often can change what we prescribe also. Because we're not going to start something IV, for example, if they're not going to have an IV at home. It's helpful. (I5 00:26:29)

The goals of palliative care included symptom and pain management, but as can be seen through the statements of team members, these goals moved beyond the physical to care for the whole person as he or she adjusted to the reality of a life limiting illness.

This strong connection between the goals and the patient-centred focus of palliative care was also seen in the team member's commitment to clearly articulate the goals of care with patients. Although adopting the goals of palliative care can be a significant shift for patients (I11 00:30:02; I11 00:56:12), the team's ability to clearly and patiently articulate these goals facilitated communication with patients (I10 00:27:43). This did not always mean that patients completely abandoned any kind of interventive care, as one homecare nurse explained:

If they're of the mindset that they want to fight it, that's okay. We just want to be here to help you with pain and symptom management. If you're going through [...] chemo than that's okay, we're here to help you. We don't put any time limits on anybody - I mean when they're assigned to us or when they're referred to us, there is the expectation of a prognosis of less than six months. On the other hand we've had people on for years - not many people, but some people - and some people we've had on for two weeks or two days. (I7 00:10:04)

Team members stated that that they needed “to gauge when someone is ready to switch their focus” from seeking a cure to accepting their terminal illness, with one of team members explaining that she found “patients are often quite good about knowing when that time is”

although “families have a much harder time with it” (I10 00:29:45). Often discussions around the goals of care could be moments for education with other teams at the hospital (I10 00:54:27) or with patients. As one team member related,

Sometimes I think there's a lot of education we can do and explaining what they're actually asking for. I mean I can think of some people who say, "I've heard those fentanyl patches are great! I want one of those for pain." And they're not even on Dilaudid yet, or something like that. They don't understand a lot of the whole system. Or they're wanting a CT scan - "why can't my GP get me a CT scan?" Then when you go back and talk to them about why they want it and what we would do with that, it's a lot of education that can break away a lot of that - we're not so far apart. I know there are situations where we just have to say, "no," but a lot of it is much [...] gentler - like the conversation [I6] mentioned. (FG I11 01:01:40)

Other times, these conversations could be much more challenging, as one participant shared her experience with a man who had moved to the palliative care unit but was unaware that resuscitations were not performed in that part of the hospital:

It was a young gentleman who was coming in for symptoms that were out of control. His disease was probably within the last months of illness - [...] maybe three months, four months - but his family could not accept a no code. And one nurse asked the question, then came out kind of, "oh, what do I do?" And then went back in with our nurse coordinator - just to clarify - and came back and spoke to me, and then I went in. As it would always be, it was Friday afternoon at 4:30 in the afternoon, and there [were] no hospital acute care beds in the system and the only place that this individual was going to go was into overflow in emerg. And then we wouldn't be MRP. So that individual agreed to be a no code. But it was definitely a point of discomfort for me, and I spent probably fifteen minutes with them saying, "I'm sorry we don't have other space to offer you, but for the sake of what we do here on the unit, perhaps you can understand that bringing in noisy resuscitative teams when death is [anticipated] - or is not unexpected - would be counter productive." He could wrap his head around that for the others, just not for himself. So that was so awkward. But he chose not to move bed space - he was already beginning to take that 'deep breath' of settling in. I didn't have another good space to move him to, so I don't know if that was part of his choice. And then by the time the weekend was through and we had actually gotten on board with the symptom management, he was feeling better and he went home. And I think he was full code once he went home. He was just a do not resuscitate while he was on the unit. (I12 00:35:53)

Given the sensitive nature of conversations regarding end-of-life care, palliative care team members felt very fortunate to be able to clearly state their own objectives because this allowed

patients and other care teams the choice of either accepting or declining the services of the team (I9 00:26:27).

Palliative care team members seemed confident that in the vast majority of cases, a patient-centred approach and clear articulation of the goals of care facilitated the provision of holistic care. In rare circumstances, however, the team had to remove themselves from the care of a patient (I9 00:33:54) because, as one physician stated, in situations “where as a physician you [do not feel] free to do your job, then it [is] right for you to transfer care” (I12 00:33:49). Such situations were usually the result of a misalignment of the goals of care between the patient and the team, as this same participant shared,

So in five years, I think I've transferred out of the Unit two or three people. Some of that was on goals of care - on expectations of care - on the patient's part, or on the family's part, or both. And when those can't be aligned, I felt it was better to not remain most responsible physician because my treatment aim and agenda was very different than what theirs was. So I think we need to make sure when we're entering into consult relationships with patients and families that they understand what it is that we're about and what kind of care we will provide. A lot of patients coming into palliative are still on palliative chemo, they're still receiving blood transfusions, but we're not going to be running high dose IV fluids, central lines, etcetera - unless it's for symptom management. That's just not what our nursing mandate is. I can order it, but I don't have the nursing staffing to actually perform it. [Also it isn't in the dying patient's best interest.] And the same with tests. There's so many families that want: "can't we just do a CT scan and see where things are at?" [...] Because that's how they've been measured all of their disease trajectory - if it's been cancer - they've been measured by having scans. So to come into palliative and not have scans is so foreign and hard, and I have to explain that actually as the keeper of the whole system, I only have the right to order tests that [are] going to change my management. (I12 00:31:25)

Another participant stated that disagreement on goals could signal that palliative care was “not what they need at this point in time, or we're going in the wrong direction according to the family's philosophy or their interest in the medical directions,” and it was helpful that the palliative care was “able to back off” (I9 00:18:13). This participant elaborated, saying,

Our philosophy has a lot to do with what's best for the patient and minimizing burden. And a lot of people [...] these days equate acute care with prevention or stabilization of your

disease. So they don't understand that the vital signs that the medical nurse is taking may not make a difference to your day to day care - in fact the blood pressure cuff hurts when you put it on and you're on a ward that if your blood pressure goes down they're really not going to do anything about it anyways. So we can get frustration and anger from families who are expecting more - more acute care. Sometimes in the extreme cases, palliative care has moved people off of the unit and put them on the medical ward so they can be provided with what they want. (I9 00:44:34)

Another team member felt that palliative care would benefit from giving patients more latitude to fight their disease, saying,

I think there's an idea on palliative care that if we don't accept the fact that we're dying that there's something wrong with us. Why should everybody come to palliative care and just make peace with the fact that they're dying? Why can't you fight it every step of the way? Why can't you rant and rave and say, "this sucks." (I6 00:28:41)

While disagreements with patients over care could result in a transfer of care, team members related that it was often more difficult to address disagreements with family members. In some situations, family members would have a more difficult time adjusting to the goals of care, focusing on a cure long after the patient has come to accept their terminal illness. Again, such situations required the staff to engage the families in patient education about end-of-life care, as one participant explained,

There's a lot of tension about how interventive to be - that's especially found in the area of fluids and in nutrition. It is universal that we eat to stay alive. [You and I] meet at a meal hour for this interview and I order soup to have lunch. If I came to your home, you likely would find something to feed me as a gesture of hospitality and as a gesture of kindness. Dying patients are no different, and their families really want them to eat because if they're eating then they're still going to live, even if their disease has taken them to the point where eating is no longer comfortable - where the nutrients aren't really available to the body after they're swallowed anyway - where symptoms actually flare because, say, of liver metastases, etcetera and trying to eat. [...] Families just can't easily understand why you don't feed. Even if we explain one day, then there are two or three other relatives wondering the same questions the next day. We've had people on their last hours who are barely responsive or awake and family are still trying to coerce things down their throat. So again that acceptance that death is coming - that release [.....] of their loved one - and then that tension between, "well can't you just start an IV?" And the difficulty of explaining, "yes, I could, and that would extend this kind of time. It would not bring your loved one back to a level of function [where] they would enjoy health or vibrancy again. They would



just have this time of sickness longer. That probably - in palliative medicine - is one of the biggest challenges after buy-in on certain medicines, for me. (I12 00:20:59)

Another participant related a situation in which the patient and a family member disagreed about the patient's medication:

I have been in a situation where a family member did not want [the patient] to have medication that [the patient] wanted. So that creates a little bit of a dilemma. So in this specific instance [...] this man had a respiratory disease - he was having a lot of trouble breathing and was becoming very panicked, and that's a hallmark of respiratory diseases. You can't breathe - it's scary when you can't breathe. [...] So I was going to give this man a medication that - it doesn't suppress the breathing - it's Versed, it relaxes you, it makes you - it gets you chill. But in this man's case, because he was having so many other medications, just that medication would also make him sleep, which is a side effect of the medication. It's a relaxant, but it's not a sedative so it's not supposed to make you sleep, but it will make you relax so you can sleep if you need sleep [...] So his [family member] was in with him, and I went in and the man is clearly looking panicked - he can't breathe; he's having a tough time and he's clutching the bed rails. And I asked him if he would like Versed. And his [family member] kind of got in the middle of our conversation and said she didn't want him to have it because it would make him sleep and she wanted to spend the day with him. So I had to explain to her this is not about her, this is about him and his needs. "Do you want that medication?" He said, "yes, I do." And she said, "[...] do you want that medication that will make you sleep?" And he said, "yes." I went and drew it up, and I gave it to him, and she was furious, absolutely furious. So in situations like that: his needs have to come first. It may be a difficult conversation - and it was a difficult situation for the rest of his time there, just because she was so furious. (I6 00:14:33)

When approaching these challenging situations, participants shared a number of strategies they used to engage patients in a way that respected the whole person. In addition to the tools already mentioned, team members reported that they tried to find times to meet with patients that were convenient for the patient (I12 00:16:31), that they were welcoming of families (I6 00:37:42), and that they keep both patients and families involved in decision making (I3 00:09:19; I12 00:17:41). Team members also reflected that music aids in healing when other approaches may come up short (I8 00:12:06; I12 01:00:17). Another participant felt that the palliative approach to non-interventive care was the key to ensuring that care remained focused on the patient's best interests:

Just because you can do it doesn't mean you need to do it. So to look from that point of view - and also to ask, to remember to find out where that person is in their journey, and what do they want? People do not get asked that - they don't get asked that. We've seen people really, really, really end stage [who've] never been asked about resuscitation. (I5 00:55:07)

Several participants mentioned the great value of showing respect for patients (I1 01:01:27; I6 00:31:46) and keeping patients engaged by giving them as many options regarding food, clothing, etc. as possible (I6 00:42:06). Keeping the patient engaged also included trying “to get the patient to do as much as they can on their own for as long as they can.” For example, “if somebody can wash their own face, why shouldn’t they wash their own face?” (I1 00:48:43).

During their interviews and focus group, it was clear that palliative care team members credited their successes to their patient-centred provision of “a whole care that takes in that whole person” (I9 00:00:18). One participant related a challenging situation in which the team’s holistic approach to care secured a peaceful death for a patient:

Our success stories always have happy and sad endings. Because usually the stories that I think about that are success stories for me in my work are always patients dying where they want to die - but they still die. So I guess I'm thinking about that lady that I was telling you about a minute ago, who was on the BiPAP, who got sick quite quickly. And the nurse coordinator who I work with was involved in the case a bit earlier on in the day, and when she first got called in, the family and the patient disagreed about the course of treatment. There were some antibiotics that another member of the [non-palliative care] team said would make a big difference to this patient, but the patient was unfortunately too sick to benefit from them. So then the family was very agitated - this woman's children were just desperate to help their mom however they could, and that was causing a lot of friction between the kids and the patient - you add in the husband, who was a second husband, not the kids' father - then you add in the healthcare team who was sending mixed messages to the patient. There was a lot of friction that I've heard about - luckily a lot of that got sorted out [with the nurse I work with] before I walked in - just the luck of the timing of it. Ultimately the patient did not want a lot of aggressive interventions. The patient herself was one of the few people in the room that knew how sick she was and where this was going. And so, again, it was just we took the time to talk with the family; we took the time to listen to the patient - and she told us. And in the end - later on that day - we ended up sedating her and taking the BiPAP mask off. And she died about an hour later. It was a difficult day of negotiations and explanations - going away and giving the family space - and coming back. But in the end she died surrounded by her family who came to support

her decision. And she died comfortably. And that was powerful. It was beautiful. (I10 00:51:37)

Team members stated that the holistic approach helped them to find problems that were not readily apparent (FG I2 01:01:31; FG I11 00:56:52), particularly problems that were “constantly changing” with “people’s emotional and mental states” (I10 00:29:20). Holistic care also helped “ease some of the burden at the end of life” (I5 00:10:19) and ensured that patients felt valued, as one participant shared in the story of a patient who she felt greatly appreciated the care he received:

[When the patient] came to us they were a mess - and a lot of the people are because their pain is so out of control; they're out of control; their families are out of control; just everybody, and everybody is stressed to the max and burnt out. And this particular man - it got to the point where they couldn't even shave him because it hurt so much. Not just the skin, but the motion of them taking their hand and shaving themselves. They couldn't do that anymore. They came to the unit dishevelled, unkempt - and there's a lot of patients that come like that. They come either unclear, dirty - not necessarily taken care of as much as they could have been. But they come into our unit, especially this man, and he was just so appreciative. [...] I think he kind of held back a little bit when he first came to us because he didn't know what to expect. He probably was concerned, you know, what were we going to do with him? How were we going to deal with him? And if we were going to be respectful and show him dignity. And we did. The day before this gentleman left, he says to me, "I don't know how I'm going to do it without you." (I1 00:40:19)

Several team members mentioned that supporting families can often result in positive outcomes for patients; this was particularly true in homecare where “sitting with a client's wife, or spouse, or daughter, and talking and giving them the support means they can do this job way longer” (I11 00:41:57). Another team member observed that,

Usually when people know that their voice is respected and valued as family members, and they see the attentiveness of the staff, usually that allows them to relax and just be family. Just be present as the wife, or the daughter, and it takes away that caregiver responsibility so that they have hopefully the safety and the comfort of the hospital, but the safety and the comfort of home as well. [...] Because sometimes the best medicine really is family, no matter how wonderful the staff is, it might be the family that really is that calming presence just because of the history. (I2 00:15:57)

Other team members related that more challenging situations were resolved due to the patient approach of palliative care. For example, one participant shared,

Well I find that if somebody is actually angry, there's usually something else going on. Maybe they are angry because they're trying to abuse their medications and I'm not making that easy for them. But maybe they're angry because - some of our patients, for example, have dealt with long standing pain and not had it adequately treated. So they've suffered for a long time in a system that doesn't necessarily believe that they have as much pain as they do. So I think any time people are angry, you've got to figure out why. Because there can be a big part of the story that you're missing - you [could] just think, "oh, I'm not dealing with you because you're angry that I'm not giving you opioids." [But] usually it's more than that. (I10 00:37:21)

The successes attributed to the holistic approach to patient care had the added effect of reinforcing the team's commitment to their work (I9 01:15:41), as several team members mentioned that they were motivated to remain with palliative care because they are able to make a difference in people's lives (I1 00:02:14; I5 00:10:19).

While participants understood that palliative care patients are at unique stage of life (FG I6 00:42:21) and that the palliative care team has access to resources that are lacking in other areas of the hospital (I2 00:12:57; I5 00:38:55; I6 00:06:16; I8 00:40:28 I0 00:46:23), several team members felt that a more holistic, patient-centred approach to care benefited patients throughout the Health Region (I2 00:49:44; I11 01:06:46). As one participant shared,

From a homecare [perspective], [...] I think sometimes other wards don't understand the home situation. So what people might be going home to or not going home to - what supports might be in the home, what family support system might be there - or not there. I don't know if it always makes a difference going home - structurally - but that's a huge difference for us: what family structure is actually out there. What the home setting looks like. Are there stairs? Are there bathrooms? Is there money? All those kinds of things - we see that when we walk in the door. [...] Sometimes people go home and it's not a possibility for them to function in that home but the hospital may not know that. (FG I11 00:47:40)

Suggestions ranged from encouraging other units to adopt palliative care's welcoming attitude towards families (I6 00:38:14), to promoting a better understanding of how conventional

medicine might collaborate with complementary medicine (I12 01:17:48), to advocating for more resources to support arts in healthcare (I8 00:47:54) and to improve staff to patient ratios more generally (I7 00:54:28). One participant shared that often moments of suffering occur that could be avoided if healthcare professionals were more honest about the feasibility of the goals of care. She elaborated,

For oncology - that's the area that I work in really [...] - what I think would be so helpful would just be to really look at the efficacy of a treatment and what are we doing? What is helpful for people? (I5 01:04:24)

Similarly, other participants stressed the need for more education for healthcare professionals on holistic approaches to care, including art and music therapies (I8 00:51:45; I9 00:42:21), with one participant stating:

There's a lot of teaching units at [the hospital]; there's a lot of young, eager physicians who want to fix everything. And patients don't always want that and I feel like sometimes I'm an advocate for the patients because the system can sometimes swallow them up. And there's a real momentum that the patient gets caught up in. And sometimes they just need somebody to say, "okay, wait a minute. Is this really what the patient wants? Let's ask." So I feel like that's a big part of our role. I don't know if that came out right... (I10 00:54:27)

Participants were generally positive about other areas of healthcare, with one noting that other areas of medicine have already adopted much of the patient-centred approach that was once unique to palliative care (I3 00:42:21).

The palliative care team's approach to holistic care was patient-centred and process-orientated. This approach was dependant upon the team's ability to make time and emotional space for meaningful conversations about end-of-life care, and was facilitated by various strategies employed by team members to communicate with patients about the goals of palliative care and to help the patients and families in their care to feel comfortable sharing their goals and concerns. To truly benefit patients, the holistic approach to patient care required the support of

strong, authentic relationships that are rooted in the consciences of individuals. These last two themes, real relationships and engaged consciences, will be presented in the following chapter.

### **Summary**

This chapter has presented the first part of the findings gained during the first phase of data collection of this study. In this phase, I provide findings from the analysis of the transcripts of eleven interviews and a focus group with members of the SHR's palliative care team. During my analysis, five themes for the deliberative processes of palliative care emerged: clear communication, a collaborative team approach, holistic care, real relationships, and engaged consciences. Of these themes, clear communication, a collaborative team approach and the team's focus on holistic care were the easiest to observe and were explicitly identified by participants as important tools for the provision of high quality patient care. The palliative care team members who participated in this study unanimously agreed that their team provides holistic care that is patient-centred, and in the stories shared by team members, I observed that clear communication and a collaborative team approach served as means to achieve the goal of the provision of holistic care. The tools related to these themes, such as active listening skills and team meetings, were described by participants as being intentionally cultivated and indispensable to their work. In the following chapter I will turn to the final two themes, real relationships and engaged consciences, and in Chapter Six I will provide a more complete analysis of the relationship between the five themes.

**Chapter Five:**  
**Palliative Care Team Findings:**  
**Real Relationships and Engaged Consciences**

**Introduction**

The first three chapters of this dissertation identified the purpose of this study, selected literature on the topic of conscience, and the methodology used in my research. As outlined in Chapter Three, the data of this study were gathered to provide findings for each of four research questions. In Chapter Four, I presented the first part of the analyzed data collected from the Saskatoon Health Region's palliative care team. In this chapter, I present the remainder of these findings, which include insights into the role of conscience in palliative care. In Chapter Six I present the findings from the two interpretive panels, and finally in Chapter Seven, I bring these findings into the context of the literature reviewed in Chapter Two.

**Five Themes for the Deliberative Processes of Palliative Care Continued**

During the analysis of the data collected for the first phase of my research, five decision-making themes emerged both explicitly and implicitly from the comments and stories shared by the palliative care team members: clear communication, collaborative team work, a holistic approach to care, real relationships, and engaged consciences. In the previous chapter, I presented evidence to support the first three of these themes, which are comparatively easy to observe and were explicitly referenced by palliative care team members in their interviews and focus group. In this chapter, I will present evidence to support the two themes that are more challenging to observe directly: real relationships and clear consciences. This chapter will continue to use the referencing system established in the previous chapter.

Real relationships and clear consciences were the final themes to emerge in my analysis of the data collected from the palliative care team. During their interviews, participants shared many stories that highlighted their commitment to holistic care. Throughout these stories, I observed that the provision of holistic care required a personal connection between the patient and the healthcare professional. When I presented this observation to participants in the focus group, all six participants agreed that authentic relationships were required to understand the needs of their patients. As I will detail in my analysis in the following section, participants indicated that these relationships required them to engage their whole selves to gain the trust of those in their care.

Participants discussed the need for real relationships with ease; however their discussions of conscience proved to be more challenging. I had anticipated that a few participants would have reflected on their ethical reasoning or previously articulated this process before my research. During the interviews I asked only one question that directly addressed conscience because I did not want the interviewees to become fixated on this word. As a means of teasing out their descriptions of their ethical reasoning, I used other questions to prompt stories regarding challenging situations that had an ethical dimension. From these stories, I began to understand the role of conscience in the palliative care team's deliberative processes and was able to articulate a descriptive definition of conscience that highlighted this role. In the focus group, I relied upon six participants to tease out a more robust definition of conscience, which is presented in the section on conscience in this chapter.

In this chapter I provide evidence that the holistic approach of palliative care was supported by the palliative care team's ability to form real relationships with each other, as well as with patients and families. These relationships were rooted in the team members' abilities to



bring their whole selves to relationships, most notably by keeping their consciences engaged in their work rather than by isolating this part of themselves from their roles as caregivers.

### **Theme D: Real Relationships**

During their interviews and the focus group, palliative care team members shared their commitment to authentic relationships with their patients as they described their provision of holistic care. For example, one participant provided a powerful statement of the value of real relationships as she shared an experience with a family member of a former patient, relating,

When I was working in the community doing palliative care, and it was a bereavement call for a gentleman who was 93-years-old, and he used to walk me to my car. When I drove up he would come meet me and walk me in. And he had asked me if I was married, and I said, "no." [...] So there's two thoughts of training. One would be to say, "and can you tell me why that's important to you?" - and not answer - to totally deflect. But I was going into his home. He was sharing how he'd been married for 65 years, and when I left to go back to school, he walked me out and said - [...] probably the most profound of all the time I'd been with him - he told me that I reminded me of his wife and that he regretted - he wanted me to get married. He regretted spending so much time away from home and he wanted me to be happy. He wanted me to have a relationship and I think he was trying to teach me that that was more important than work. So there is being caring and creating a safe space that's very intimate when you're talking about death and dying and your most intimate pieces. And when you are going into people's homes, it's not a clinical setting. There's pictures, there's stories, there's that whole person's life of who they are and how they've become that, and I think they test you to see if they trust you enough to share the vulnerabilities and the things that are most private to them. The psychosocial and the physical are so intertwined [that] you have to have that relationship to be able to do the other pieces no matter your discipline is. No matter whether you're the cleaning staff or the physician or the nurse - you have to have a sense of relationship and trust. (FG I2 00:35:31)

The personal connection and trust outlined in this story were also present in the stories of other team members. As one participant explained, forming relationships was an indispensable component of the care the team provides:

It's the connections that I make with people. It's very personal. It's very special. It's individual. And [one in] particular: it was fun! It was fun! I loved coming to work. I absolutely loved coming to work, especially in palliative care, because I get to see this person and I get to see the smile on their face and joke with them, and have fun with them.

And tease him, and he teases me. And its a two way street, and that's this relationship that's happening, and I absolutely loved being with him, and vice versa. [...] That's why I continue doing what I do! And that person went on, and it was hard for me to let go because I got attached. And I tried not to get attached, but I did because I was building this rapport with this person. And I was treating him like a human being, not just like a number, not just like a patient. I was treating him probably in the way I would a friend or a loved one, and I had the highest regard for him. And, near the end, and its just the sparkle in his eye - I don't know, the twinkle - it just made you feel good and you knew that you made them feel good. And you knew that you were special to them and important, and according to them you were a beautiful person. And near the end, I even got a chance to sing with him. And when he took his last breath, I said goodbye. And when they took him away, I actually had to wipe tears from my cheeks because I miss him. Every time I go into that room, I think he's there but he's not anymore. But that's why I do what I do. (I1 01:07:00)

Another participant articulated the importance of relationships in gaining the trust of patients who were near the end of life:

When you meet people really near the end of life, you're limited in terms of how quickly they trust you and how quickly you settle symptoms. Because symptoms are never just physical. They're always such a blend of how we think about our life, how we think about our relationships, how we think about who we're leaving behind, and how we maybe get ready for that or don't. (I12 00:45:27)

In this section I explore the role of relationships in the provision of holistic care to patients and I highlight the ways that team members built relationships in palliative care services.

### **Relationships with Patients and Families**

As noted in the section on holistic care in the previous chapter, palliative care team members had unique ways of viewing their patients. One participant explained the difference between palliative care and other units of the hospital, saying,

When we're looking at someone that's on a surgical unit [...], we are approaching that relationship as, "you are here for this amount of time. We expect you to make these certain marks, and then you're going to go home and you're going to carry on with your life." Whereas a patient in palliative care - we're not looking at how you're going to go - we're not addressing that. We're addressing: "you're family here and there's no beyond this." [...] We're not looking to get you somewhere else. We're enjoying you for the moment, and we're not looking at the goal of where you're going to be in a week from now. So the relationship is completely different. We can build on that relationship whether it's really short or really long, and we don't put the constraints of the surgical attitude on it. [...]

We're more willing to look into getting to know your family - getting to know your past history. We want to know that because that defines who you are. (FG I6 00:40:38)

Team members explained that their approaches to their patients stemmed from their ability to see their patients as persons in their own story, with one participant commenting, "it says a lot about the relationship [between team members and patients that the stories] are just as important as the medical diagnosis" (FG I2 00:40:24). Another participant elaborated, stating,

I think all of us that work on palliative care value the patient's story. And that is things like, "tell me about your wife. Tell me about your kids. Tell me what you did when you were a working man?" We embrace those stories as much as we can. I know sometimes for the nurses doing the actual clinical work that's difficult - they're very busy - but I know they do find those stories out as they're bathing the patient or as they're feeding the patient. It's not like they just sit there like robots. I think they use that time therapeutically even if we don't realize we're actually doing therapeutic things with that patient as we're asking them about their grandchildren. I think some of us think, "oh, we're just making small talk," but that's the whole part of palliative care, I think, that's so important. Because it's not "the man with cancer of the pancreas" in that bed. It's Mr. Smith that has a wife and raised three kids and was a farmer and is now a grandpa. That's who's in that bed. It's not "the pancreas." In fact I think most of us don't even remember what's wrong with half our patients as far as a medical diagnosis. (FG I3 00:38:57)

This participant later put her thoughts more simply, stating: "I think people like to tell their stories, and I think they really like being a person not a pancreas" (FG I3 00:43:57). Several participants spoke about the value of getting to see patients in their own environment (I7 00:02:31), with one participant articulating that she appreciated seeing patients "with the pictures of when they were married and their kids and their families and just everything being a statement of who they were and what their life symbolized" (I2 00:02:53). Similarly, other team members stated that they preferred to be connected with patients early in their diagnosis to have time to develop strong relationships (I12 00:09:38), and that as soon as they meet patients, "they are part of [the palliative care] family" (I9 00:19:39). Still, team members also recognized the importance of not forcing relationships with the people in their care (FG I2 00:54:46) and appreciated that it takes time to develop meaningful connections (FG I2 00:38:29).

In keeping with their holistic approach to care, the palliative care team also valued the relationships they were able to build with families (I6 00:10:00; I7 00:59:22). This was important not only for the well-being of families themselves (I12 00:23:39), but also for the well-being of the patient (I2 00:15:57). As one participant explained, “it's important to see that patient as part of that bigger family unit because those dynamics and those supports are going to affect that patient's experience” (I10 00:07:30). Team members related several ways they had tried to reach out to families, including by being open to having family members stay overnight at the hospital (I6 00:33:01) and ensuring they were involved in meetings regarding patient care (I11 00:21:46). As one participant related:

We try to have as much conversation with family as possible. And that's always with consent of the patient as well. I think what we recognize is that patients aren't in isolation; that they have been cared for by people in their homes before they come here. Their caregivers have an expertise as well as to what is the history. And sometimes when we meet people they're not able to share what are the things that are important to them, or give feedback on how we can best care for them, so we get that information from the family. (I2 00:22:47)

While the relationships present in palliative care certainly had an intrinsic value (I9 01:07:42), they were also valuable because they improved the palliative care team's ability to care for the patient (I11 00:33:28). As one team member explained,

Sometimes it's important for us to get a relationship with [the patient] before we can talk about some of the hard issues. So - I want the patient to be as open and receptive as they can be to us being there - so that we can get to that stuff. (I10 00:17:35)

Participants shared their views that relationships among family members become even more important as the patient coped with the realities of dying (I8 00:03:05; I11 00:13:36). As one participant explained,

I think the c-word - the cancer word - allows people to go, "okay, what's important in life? What's the priorities here?" Or what's on their bucket list, or, "[who] are the people that I really want to spend time with?" And it's often family that becomes the important thing. (I11 00:56:12)

Another participant shared the story of a man who drew support from both his family and the palliative care team during a difficult illness:

I think for me that's it - the priority of being known is so much higher - to hearing what that person's story is and to have them have the sense of being known - being seen totally for who they are. I'm just thinking back to a story of an individual who died quite recently on the unit who really in my mind struggled for a long time. Their spouse was very, very thankful for the care - especially some of the nurses who [were] with them when the individual was struggling. [They] never felt abandoned and always felt that people were continuing to try to make things better - to address the symptoms and always felt that they were valued and cared for. [.....]. So experienced high levels of symptom management emotionally, physically - in the end, I think what the family will remember is that she was cared for. (FG I2 00:43:57)

The relationships developed by the palliative care team, along with their genuine commitment to patient care (I1 00:45:23; I2 00:07:06; I11 00:26:12), seemed to spur team members to look for creative ways to care for their patients. For example, one participant shared her resourcefulness in keeping a patient warm:

Yeah, the biggest thing was cold. He literally was cold. And we tried almost everything to make this man warm. And I personally was trying to think outside the box - ways I could keep him warm. Even when I showered him, I'd bring him several warm blankets from the blanket warmer. And when I'd bring the shower chair I would put a warm flannel underneath him with his cloths still on, put a flannel over him and then take him down to the shower area. And then disrobe him there, and then shower him. I'd have the water running before he even got there, so it was warm. I just went all out just to make sure that it was done. First of all, I'd take him back to the room and dress him - but then I thought, I'm going to dress him right there. Dress him, dry him off with warm towels and warm blankets, just get it all done in an instant and then we'd go back to the room and get him sitting on the bed. (I1 00:43:14)

Another team member shared her efforts to ensure a patient with terminal cancer made it home:

She was still hoping that she could live for a little longer. So what she ended up doing - her son had a girlfriend, and she really, really wanted to meet this girlfriend. So what she did is - we often do this on the palliative care unit - we encourage people to go home to do whatever they need to do. She lived up north somewhere [.....] - so they got everything together and they took her medication. And she went home; she was present when her son and his new girlfriend came home, and so she spent the day there. They drove back that evening, and she died the next day. That's the kind of thing that we do - and you don't see a

lot of that in acute care. But really we try to help people to have some kind of closure. (15 00:15:44)

Yet another team member shared an experience in which the palliative care team supported a whole town in their care of a patient, sharing,

[This woman] lived in a small community not far from [the City], but [had recently moved there], so it wasn't like she grew up there or anything. She was divorced from her husband - they didn't have a relationship anymore - and had a son that worked on the rigs. Very dedicated son, but worked out of town in [another province] and could only come home periodically. She desperately wanted to go home to her home community and to be cared for there. She was almost total care. It would be very difficult to send her home with a son who wasn't there but was very caring, and physically couldn't be there a lot - and she really had no other family. So how do you do that? How do you provide care when homecare is very, very limited? And so, the minister in town actually had befriended her, and she rallied that community, and they took her home. And it was absolutely amazing because they figured out who had what strengths - so there were some ladies in town that had worked as care aids or whatever, so they were very comfortable with doing her personal care. Some of the women maybe weren't that comfortable with that, but they were really good cooks, and so they would say, "you know what? I'll do the cooking for every Monday [...]" And some of the gentlemen would say, "I don't want to do any of that, but I can do the driving. So if some of the ladies that are coming at night don't want to drive at night, I can pick them up and chauffeur them over here." Or, "I can pick her son up from the airport when he comes in," or whatever. So most of the people in that small town had jobs to do with [her]. And she stayed home and she died there. [...] And I remember talking to them - and there were so many things that it looked like they didn't have in that community - because they didn't have a doctor right there, they didn't have a CT scan, they didn't have, they didn't have, the didn't have! But they had community. They had a community that was willing to look after this basically unknown woman until her death. So it was absolutely phenomenal. [...] We helped them a little bit with showing them how to give medications a certain way, and making sure the prescriptions were there, and making sure all of that was ready - helping them, show them how you do this, how you turn somebody - all those sorts of things and providing what support we could. But they did it. It was quite phenomenal actually. (13 00:56:10)

As a final example, another team member shared her resourcefulness in finding the care a patient needed:

I had an off service patient [who] came in with this terrible rash - and it actually had gone internal and was into her throat [...]. We don't have a dermatologist here. I have lots of friends - as far as other medical staff members - I'll use whatever I need to get the patient the care they need. So I remember, I went to oncology and they scared the dickens out of me - said this was some sort of terminal illness and that I needed to get [going] because she had days to live. So - no dermatologist and medicine couldn't help. So I talked to my friend

who specializes in dermatology - she's at an outpatient clinic. I gave her pictures - I got permission from the family to take pictures of this. She was able to diagnose the issue over the Internet. [We] started up medications and it wasn't that terrible disease. Without a support - and this was way beyond palliative care - this was helping somebody find a solution to some problem - it's being a team member that maybe had a few more friendships than maybe the residents had. And the poor lady went for an outpatient visit while she was still here in hospital, got the right creams, right diagnosis. And she got home to homecare and said she was so happy with our service here because we had gone way beyond the services that were available. So that was one that I can remember. (I9 01:13:02)

The benefits of these relationships extended beyond the individual patient to the entire healthcare system. One member of the palliative homecare team explained that the care she provided often kept patients out of acute care facilities, sharing,

A client that died [awhile] ago - we kept him at home for way longer - with all kinds of support. He ended up in the hospital briefly at the very end, but he was so grateful for the care we gave. There are lots of stories like that. I get lots of hugs from people and I'm not even a real huggy person. But I get lots of hugs from people because they're just grateful that we journey with them. [We] didn't change the story - [we] made it better hopefully - a better story - but we didn't change it. Very grateful families - still mourning - that part is the reality. (I11 01:11:03)

Perhaps the best articulation of the system-wide benefits of forming relationships with patients came during the focus group session from a participant who observed:

There's more support [on palliative care] for putting into practice compassion and collaboration and how that [is developed]. [.....] On our wall we have a big sign that says, "all about the flow," and I think patient flow and money and reinventing how to do everything [...] - it is about cost. That's the bottom line - and how to get people through. I think we miss the fact that if you have that relationship - if people feel seen and heard - I actually believe in the long run it will benefit the system, but you need the higher ups to make it - not just give lip-service to the value of compassion - but to make it a concrete part of the work that we do. Concrete in the sense of patients leave feeling that they were cared for. (FG I2 01:06:46)

Participants felt that palliative care's focus on relationship building could be beneficial if applied to the rest of the Health Region, but that this would require a real commitment to develop the tools needed to foster trust among healthcare professionals, patients, and families. These tools are the subject of the next section.

## Developing Relationships

In their discussion of relationships, it became evident that the formation of authentic relationships required a concerted effort on the part of team members. As one team member explained, forming relationships was particularly challenging if a patient had had a bad experience in the healthcare system before coming to palliative care:

[I've had] lots of patients come [to] the unit that are very disheartened with the healthcare system - like just so angry because according to them - I mean, every story has two sides - their dad or whoever should have been diagnosed and the doctor missed it, and he didn't do enough tests, and then this doctor missed it, and then - you know? And some of that might be perfectly true and some of it might be just their version of it. And they come to us and it might be all we do is sit and let them vent - we listen, and tell them we're really sorry that things went as they did, and we apologize for that - but what could we do now to make things better from now on. And so we're not telling them that didn't happen - [...] [or] try to justify any of that - because that's gone by, that's done. What we do is we listen - we don't say, "oh no," - and then we say, "okay, let's see what we can do good from now on." And you just see their faces change - like it's amazing, because they come in angry and mad - and they aren't angry and mad at us because they hardly know us. But they've been - in their minds - so disheartened by the healthcare system and in some cases they feel that's why their loved one's dying. And then they come up against us, and we're part of that system so I think they just expect the same from us, or that we're going to defend the system and say, "no, that didn't happen." And they get this other response from us, and it's huge because now we can work with them. If we get our backs up and say, "no, that didn't happen," and argue with them, that's going to do nobody any good. That's not going to do the patient any good; it's not going to do the family any good; and it's not going to do the team any good because we'll get nowhere with this patient and family. (I3 00:16:37)

In addition to the skills and tools already discussed, participants also drew attention to the value of creating trust with patients and families, maintaining honesty, and developing relationships with fellow team members, as ways to create an environment that fostered the relationships needed for patient-centred care.

Several participants remarked that the palliative care team had the trust of their patients (I8 00:22:52), a necessary component of any health relationship, and they were able to list several skills and strategies that helped them to build this trust. In addition to being personable (I9 00:16:33), team members also stressed the importance of maintaining relationships by being



present to patients and families, even when the patient was feeling well (FG I11 00:55:42). One participant elaborated on the importance of remaining present, particularly for patients with long-term palliative illnesses, saying,

Palliative care nationally is encouraging us to open up doors to non-malignant cases - [to] the cardiology, neurology, respiratory cases that aren't necessarily malignant in nature. It's a scary thing for us because prognosis is so difficult to figure out. But if you take a look at the essence of palliative care - and that's symptom management for anybody with a life-threatening or terminal illness - timing doesn't matter. Everybody's going to have those good and those bad periods, right? As long as we stick around on the edge while people are having their good times and not just discharge them. Because you know with non-malignant cases that's what's going to happen - this yo-yo kind of thing. And be there exactly when they need us when things fall apart - that's the philosophy we've got to take with our non-malignant cases. You've just got to be sensitive to timing. (I9 00:31:54)

Music was singled out as an important tool to help patients feel more comfortable with the palliative care team:

So many conversations are shared after a song. I've just heard so many little stories, and I don't always know what necessarily the patient's experience is when they hear a song. They might share it with me. [...] Often I would say that life-review is a technique that's used in music therapy - a lot with music therapists - so that means that special songs from the past might be shared. So for instance that could be songs that they sang to their children, or wedding songs, or songs they remember from their honeymoon, or anniversary songs. So those songs are often brought up, and I have a song list. So I might say, "take a peek at my song list, and if there's something that comes to mind or jumps out at you, let me know." And then so often after music is shared, we share a lot of conversation. And I think that it's really emotional. It's impossible to separate the emotion from the music and your past memories. (I8 00:20:29)

Participants stressed the importance of non-judgemental care when building trust with patients because, as one participant shared, “our patients [and families] are so vulnerable, so you have to come from the right place [...] no matter what they've done in their past” (I3 00:44:12). As with relationships in general, building trust required time to allow patients to understand, as one participant said, “that you want to be there – that you genuinely care about them” (FG I11 00:47:09). Building trust was singled out as being particularly necessary before entering into

conversations about challenging subjects, such as resuscitation planning. As one participant explained,

I don't ever think [resuscitation] should be just the [sole] focus of a conversation. It certainly should not be the first thing you talk about with people because again it's just not trust building. (I12 01:15:51)

Although participants acknowledged that it is challenging to establish trust in short periods of time (I10 00:30:23), they also stressed that it was important to gain the trust of patients and families “as quickly as you can” (I10 00:22:00). Participants remarked that establishing trust contributed to the provision of holistic care because it helped the team members to establish “a good rapport” with the people in their care (I7 00:25:49), which can greatly facilitate conversations around end-of-life (I9 00:48:58; I12 01:21:50). This rapport was useful when patients ran into difficulties because it helped families relax and focus on their being with their loved one (I2 00:15:57). It can also help families to feel comfortable sharing their concerns (I8 00:54:41), as one participant shared,

I can't say in all the years that I've had somebody - once they feel comfortable with us I think the families are feeling that they have the right to voice any concerns before we get to that point. I think that [anger] happens when they use us as an advocate - or a set of ears - to describe their frustrations with the rest of medicine or with the rest of the hospital. Once we've established a good relationship, they don't necessarily get angry at us. I can see it happening though - we move from one area to another and you hope that the rest of the team members follow through with what you've requested or what you've set up. And you know the nice thing about it is that - with our community, our palliative care - we do all have the same thoughts about how we want to treat people. So when I move somebody from one service to another, I don't often find that families get frustrated that way either. I think it's more they get frustrated with the system. (I9 00:42:06)

Building trust between the team and patients and families was challenging and time consuming, but it was clear that participants felt this was an indispensable part of the care that they provided around the end of life.

Alongside creating trusting relationships with their patients and their families, palliative care team members also stressed the value of being honest with those in their care. Being honest with patients was important to the palliative care team because, as one participant explained, “you injure a person if you’re not being truthful with them” (FG I2 00:58:26). She elaborated this point, saying,

The most important thing for me when a person is vulnerable is always: they need to trust the people that are caring for them. So to me, the difficult conversation is not dictating what the future is or that your voice is more important - ultimately patients make their own decisions and we respect what those pieces may be. An example would be: We have a gentleman who wants to go home to live. He hasn't been out of bed in over a month. I don't believe physically he'll ever be able to walk again. So I had said, "if I'm honest I just don't know if that's possible. What if we work at smaller goals and see if we can't work towards a day pass. So for me it's part about being honest without taking away - because I can't predict the future, I don't know for sure what will happen - but when people ask or look for some feedback - so when somebody's asks the physician if they're dying - to me, you have to trust that people who care for you are going to tell you the truth. (FG I2 00:58:26)

However, being honest with patients was not always straight forward, particularly in a system with limited resources:

We had a patient recently go to long-term care. A family member of that patient is in the healthcare system, and when we were talking to that family member [a while ago] about looking at long-term care for [his] relative. He looked me in the eye and said, "will he get as good care there as he does here?" My lying answer would be, "yes" - if I didn't have a conscience - because the system would want me to tell him that yes the care is just as good so that he doesn't balk the system and say, "well, I don't want him to go there. Why would I want him to go there if the care isn't as good as here?" The truth would be: No, it's not as good. Not because nobody tries - they try their darnedest to give good care - but it's not possible to give the care there because they don't have the staff to give that care. So how do you balance that? If I didn't have a conscience, I'd lie and say, "oh sure." If all I cared about was him signing that thing saying, "yes, my family member can go to that nursing home." [...] I feel really bad because that discharge to that nursing home did not go well, and he did not get his pain medication, and I feel horrid - horrible because I probably - I don't remember exactly what I said to that family member - but it was probably something about, "oh well, you know," - something that wasn't a lie and yet something that wasn't [the whole truth]. (FG I3 01:03:37)

In situations regarding patient transfers, this participant also emphasized the importance of “[acknowledging] with [families] that their loved one does need care and that [the team wishes

they] could keep them” on the Unit (I3 00:36:51). Other team members focused on the importance of knowing their limitations when patients were asking for services or information beyond their abilities (I11 00:27:35). Given the delicate nature of conversation around the end of life, team members stressed that honest conversations, particularly ones in which the team are not able to provide patients with what they are looking for, must be carried out in the context of a trusting relationship. One participant explained:

I guess in a publicly funded system, we still are the keepers of the care of the patient and the good of the system - that's a tough tension. So when we have requests that we have to say, "no," to, I think we want to be truthful about why we're coming there, but I think we also want to [have] trust built already so that they don't feel like it's a confrontation. But there will be individuals that leave from whatever conversation that has that content - conflict - in it feeling wounded. That will probably be more to do with their feeling like they're a client or a customer, and that this is their right to have this, to have this particular treatment and, "how dare you say it isn't my right." So there would be hopefully - I think we are masterful - I think all of our team are masterful at not [being abrupt when we say no]. (FG I12 01:00:00)

These sentiments were echoed in the elaboration of another participant: “That’s the thing – it’s not just a ‘no.’ It’s generally a conversation – it opens the door to a conversation” (FG I6 01:01:14).

Participants also explored the value of developing relationships with one another and the impact this can have on patient care. One team member explained the need for strong relationships among team members, saying, “if we don't feel in relationship with the place we work, how can we provide relationship to patients and families?” (FG I2 01:11:07). As discussed in the section on the collaborative team approach in the previous chapter, team members found great value in their meetings both in and outside of work hours because these times helped them to see each other as “a little more human” (I7 00:47:23) and to develop trust with each other (I7 00:21:50; I9 00:39:32). One participant emphasized the importance of trust to maintain a healthy team, saying that she needed to trust her teammates to challenge her if she was not doing her best

for a patient (I3 00:49:06). Trust among team members was also cited as facilitating collaboration between doctors and nurses in particular, as doctors, both palliative care physicians and general practitioners, were more likely to trust the observations of a nurse they knew ((I5 01:04:24; I7 00:43:56; I9 01:03:55). One team member also highlighted the importance of developing relationships with other teams when serving in a consultation capacity:

I find the same thing in long-term care. We're just consultants out there too, but I find that I've got a good relationship with the nurses out there. I've been working with them since [the mid 2000s], establishing better symptom management. I walk into a home, we take care of a patient or a resident, and then we leave. It's up to the physicians who are taking care of that patient on a daily basis to decide whether they want to follow our suggestions or not. (I9 00:40:47)

These strong relationships among the team also helped team members to enjoy their work (I9 00:07:36) and to avoid burnout (I11 00:47:32), which enabled team members to provide better care for their patients (FG I12 01:10:28).

As noted in the section on team collaboration, participants stated that they drew heavily on their relationships with other team members for emotional support (I7 00:27:25; I11 00:06:03; I12 00:53:53). One team member explained the challenges of palliative care stating:

Palliative care - caring for the dying - is an exhausting work. I feel like part of me dies if I've done a good job. And to hold that with others that then remember the journey of an individual, their family - that we remember them together - it's really important. I think the burden would be oh so much higher if it wasn't a team caring for people at the end of their life. (I12 00:30:19)

Many team members felt that palliative care was a "safe place to say, 'I'm struggling with this piece'" (I2 00:30:39). One participant further explained:

There will be situations that perhaps touch us positively or negatively throughout the time based on whatever that situation is and I think it's a safe place to have conversations about, "how are we impacted?" as well. So a recognition I think that we come into families lives and into their circle, this very intimate and special - or significant time, anyways. And how do we - for me from a psychosocial point what I appreciate is: how do we have a space where we can try to support each other and be aware of what our own stuff is that we bring? So that our stuff is not impacting or part of the people that we're walking with or

beside. And for me that's an important piece. So, each of us might have a patient or a family member that particularly touch us for some reason, or that perhaps we struggle with a little bit more, or other, so it's nice to have that team support so that not one person carries or owns the success or the failures of that piece. (I2 00:08:01)

Another participant expressed her ease with her team members saying,

For me I feel pretty open about speaking with, for example, our social worker or our physicians. So I think if something was upsetting me about that particular patient - that I needed to speak to somebody - I would be quite free to talk to them. (I3 00:25:17)

This participant stressed that not all team members were able to capitalize on their team relationships in the same way, as some team members had less time to process challenging situations:

I think it's a lot harder for the staff nurses because they can't take half an hour and just disappear for half an hour and talk to another nurse because then you've got two off the floor and whose going to cover. You know what I mean? Whereas I can disappear for a while - I can because I don't have patients. So, I think it is hard for them and I think it depends on what your support is like outside of the hospital too. But as far as the team goes - I hope everybody feels - I certainly feel open enough to voice my opinion or to say how I feel about a given situation and that I'm struggling, maybe, with that decision. (I3 00:26:47)

Support from colleagues was particularly beneficial in situations where the proper course of action was unclear, as one participant explained:

I talk to people a lot about situations - like if it's one of those ones that keeps me up at night. I talk to our [homecare nurse coordinator] - [...] talking through sometimes is enough to get you a better understanding. (FG I11 00:28:43)

While some team members focused on the support they drew from the team (I2 00:28:29; I11 00:35:43), others felt that they had had a unique opportunity to provide a listening ear to their colleagues (I8 00:35:11) and “to figure out how to call them back” encouraging “ them to start doing some self-care” (I12 00:53:53).

Team members were well aware of the challenges facing healthcare professionals who aspired to create authentic relationships. During the focus group, one participant explained these challenges:

I think too - having a been a nurse for a long, long time, and worked many areas - gone are the days when pre-op patients, for example, come into the hospital two or three days prior to their surgery. At that time there was a chance that the nurses - or some of the nurses at least that worked on the ward - could get to know them a little bit, and got to know them pre-op when hopefully they weren't full of drugs [...]. The physician maybe saw them - even every day pre-op - and they got to meet that surgeon before they fell under the knife, so to speak. So that's not going to happen anymore - that just is not going to happen. So we have to figure out: how do we develop a relationship with the patient that we don't even meet pre-operatively - if we're talking about surgery. That they show up after they've kind of recovered and they're still kind of a bit groggy, and they're not going to be there very long. So I think trying to develop relationship and that story that we learn from the patients in that short period of time. How do we do that on other wards? Because they're not going to suddenly give us two extra days to get to know our patients before they have surgery. That isn't going to happen. So how do we teach ourselves as healthcare providers to somehow develop a relationship in that short period of time so that trust can be there at least a little bit. I don't know. It's difficult because we've made this healthcare system such that they're constantly needing different people - again, gone are the days when he family doctor cared for you almost everywhere that you went. They delivered your babies, they looked after you children even if they got admitted to hospital, looked after grandma in the hospital, they maybe even did some home visits for you, [and] they looked after you in the nursing home. You don't even have a physician anymore that knows you because the family doctors don't come to the hospital anymore - generally. A lot of them don't make house-calls, so you're seeing all these different specialists that you don't know if you can trust them. You don't know [...] anything about them. And so the whole healthcare system has changed so that building relationships - we have to work even harder at it, I think. (FG 13 00:49:19.1)

Other participants responded to these comments, with one team member suggesting a number of tools that could be useful for other healthcare professionals:

There are better means of having families and patients tell us who they are as they come into a hospital - other than having a yellow canary [card with] doctor, blood pressure, [etc., written on it] - there's really no information on there in terms of the story of an individual. So the acute care wards could maybe try and figure out if that's important. And then there are some moves towards parish nurses, and that's for the same person to know a person [and family] when they come home [...]. To stabilize them, to have homecare involved, to have respite involved. Especially when you're sending home the frail elderly - I'm not talking palliative, I'm just talking about patients in the hospital who [on] day three are going home with an 85-year-old spouse looking after them. It's such a precarious fragile

balance that knowing the story, knowing the economics of the home - who's going to get groceries, for example? Or those sorts of things that we don't - we think about them - but I'm not sure acute care medicine has taken that as a focus. Just having more importance on story and people being people, not being diseases. (FG I12 00:51:59)

This thought was continued by the comments of another participant, who stated,

There [are] ways of [establishing relationships] in a shorter time frame because I do know that there are different disciplines or physicians who when patients have interactions with them even though it's very short or concise, they still feel like they were listened to or seen or viewed and they will remember those people for the rest of time. To me it's a priority about how much value - when everything is time crunched, when we're all about the flow and we're all about money - those are sort of the buzz words - and now safety. Story is not necessarily one of them - even though compassion is in our core values - it's not necessarily, "how is that, in a practical way, played out?" (FG I2 00:53:29)

Additionally, throughout their interviews, team members provided other suggestions about how to potentially improve relationships between healthcare professionals and their patients. These included encouraging family physicians who had the trust of their patients to routinely engage in conversation about end-of-life care (I12 01:17:48), and finding ways to give staff more time to interact with patients and with each other. As one patient shared,

Bathing a patient [is something] they've taken away from nursing in a lot of cases, and bathing a patient is a whole lot more than just bathing a patient, in my mind. Just more interaction with each other even. Not that we should be gossiping at work or spending all our time talking to each other, but just supporting each other better. Having older nurses mentor young nurses. All that kind of stuff - a much better staffing ratio. (I7 00:54:28)

Another participant suggested that displaying pictures of patients when they were well could be set up at bedside, explaining that "even in acute care [that] goes a long way to speak to the personhood [of the] individual in the hospital gown in bed" (FG I12 01:09:15). Participants also spoke about the need to promote honesty in other areas of the healthcare system, particularly around the end-of-life prognoses, with one participant lamenting,

One of the things that I think is so tragic and happens so often in the hospital is we give false hope to people; we don't tell them what we know or what we think to be true. I think so much of this has to do with relationship and truth telling - as much as we can know the



truth, because we can't obviously know the truth - the truth's different for everyone. (I5 01:04:24)

As mentioned above, palliative care benefited greatly from the relationships between team members, and although bringing this approach to other units would not be without its challenges, there were simple techniques cited that might improve teamwork:

I think just knowing each other so well helps us function - and can you take that to another ward that's big? I don't know - it's difficult. Because on the other wards they're dealing with way more physicians, way more nurses - but I think even a small little gesture, [for example]. let's say you're on a big surgical unit or something and a physician comes up and says, "oh, are you looking after Mrs. So-and-so in that room." And you say to them, "oh yeah, I am. And my name's Jennifer. Hi, how are you? I'm new here." Just little things like that. And that doctor might not remember your name the next time he meets you, but he'll remember that you introduced yourself. It takes three seconds. And I think even little things like that - to [try] to know one another on a level other than a nurse and a doctor. Or going up to the physiotherapist and saying, "oh hey, I heard we were getting a new physiotherapist! My name is Jennifer. What's your name? And wow this is great! Which ward did you come from?" I mean just taking those few seconds - I think that the idea of taking that time (I3 00:50:45)

Although it was challenging to develop relationships in a healthcare setting, participants felt that setting the groundwork for their care of individuals would be worth the extra effort in areas of healthcare beyond palliative care and that the development of relationships deserved support on an institutional level (FG I2 01:06:46).

The provision of holistic care was supported by authentic relationships among all those involved in a patient's story. These relationships required trust and honesty, as well as a readiness for healthcare professionals to bring their whole selves into their relationships (FG I2 00:32:32; FG I12 00:34:13). This included keeping their consciences engaged in their work, which is the focus of the next section.

## Theme E: Engaged Consciences

As I listened to the stories shared by palliative care team members, I observed that the four themes already described were all tacitly underpinned by participants' consciences. For example, in the following story, one team members explained her decision making process:

It was a difficult disease and it was a family member who was - I think - burning out even though we were trying to get more help in there. I think she was burning out and using phrases like, "we don't treat our animals this way," and, "we should be able to do something about all this." At the same time it was a client - her mother - in distress, and [I was] trying to provide meds that she needed. But also [there were] words that she was saying that I thought, "I feel like I'm giving her the tools to actually end [her mother's] life. And it was very unnerving and I felt very uncomfortable leaving that home, and I actually at that point - I think I came back the next day and I was really distressed by it. So I think I actually put her on the waiting list for the palliative care unit fairly quickly with a bit of an understanding that this was kind of my gut feeling - you don't know. So that was helpful because she did get on to the unit and everyone got the cure they needed in that position. But I think there's an awareness - [...] it bothered me that I felt like I was giving her the tools [...] she could use overdosing. And we've been told that [...] if we were to give dilauded -for example - and give multiple doses of it, it still wouldn't end someone's life. But I was - there still was that feeling that was there. (I11 00:30:02)

In her telling of these events, this team member does not use the word 'conscience,' but her description provides an account of how her moral judgments were made and her compulsion to act on these judgments. Similarly, in their interviews and the focus group, other team members were asked about the role of conscience in their work, and although team members had a difficult time defining conscience (FG I12 00:29:02), they ultimately described three inseparable facets of conscience that helped to articulate its role in their work. These three facets described conscience as that which told them right from wrong; as that which demanded conscientious work; and as a navigation tool. Participants explicitly shared some reflections on these facets of conscience; however, most of the findings pertaining to conscience were implicit in the stories shared by team members, some of which are compiled in this section while others can be found throughout the other themes explored in this and the previous chapter.

## **Palliative Care Team's Reflections on Conscience**

In their discussions regarding conscience, the palliative care team identified three inseparable facets of conscience that helped them to form authentic relationships. The first facet related to conscience's capacity to judge right from wrong (I12 00:29:02). For example, when asked about conscience, participants mentioned that their conscience kept them awake at night (I2 00:28:29; I6 00:35:11), with one team members stating, "I don't know - I'm from the old school: I think you just have to have a good conscience. Like do it so you can go home and sleep at night. Do the best you can" (I7 00:48:09). In a similar vein, conscience was sometimes referred to as a "gut feeling" that was "important in how we make decisions," but which needed to be in dialogue with what patients want for their care (I10 00:43:29). This facet of conscience was not to be confused with a stereotypical "guilty conscience," as one team members explained that "it's not right/wrong in a guilty conscience way, but in a stirred up [way]. And then where is that just overlaid with my passion for that which is excellent care? It's hard for me to tease those apart" (FG I12 00:29:02). This same participant also described her conscience in spiritual terms, saying,

[A] still small voice - that's what I'd say my conscience is, and mine would be linked to an invitation that God's conscience would be in me, as I understand God to be. That there would be a nudge towards what is right, good, lovely, excellent - that doing harm would not be in my armamentarium of practicing medicine. And so that - within a personal context - has always been black and white on some issues. (I12 01:06:26)

Other team members also mentioned a spiritual dimension to their conscience, with one team member explaining that she needed to act in accordance with the judgments of her conscience:

I think there are times when for me - What could I live with and what couldn't I? If this happened, could I live with the consequences? [.....] So, what's in line with what I believe? What decisions would be in line with my personal stance, my faith stance? And what would it mean? So conscience to me would certainly have a spiritual component - a kind of religious connotation. (I5 01:00:06)

This participant expanded on the value of conscience in the team's care of patients as well, stating,

I think conscience - that internal sense of what's the right thing to do - I think that's a big part of what we do. And I think if we're not clear about our own solidity - about what we believe, in essence - what feels like the right thing to us to do - I think we can easily get shaken by the winds - [...] by the waves. So I think that sense of conscience really helps. (I5 00:58:35)

In this first facet, conscience clearly played a significant role in helping team members to distinguish which actions were good for both themselves and their patients.

The second facet of conscience identified by participants built on the first and was identified as that which spurred team members to provide care based on what they perceived as right or wrong, care that they described as conscientious care. As one team member said, "conscience drives [you] to try to be the best you can be. I don't think you ever hear, 'I don't have time to find out who that person is or who that family is'" (FG I2 01:10:08). As mentioned in the section on the team approach, several team members stressed that they were continuously impressed by the conscientious care delivered by their team members (I6 00:36:04), with one participant stating, "I don't know a more conscientious team that I'm privileged to work with. I have never met people who are so committed to what they do day in and day out" (FG I12 00:29:02). Conscience and commitment to patient care were succinctly tied together by another participant, who explained,

I think conscience is, "I'm still going to brush this person's teeth, and I'm still going to make sure they are clean and comfortable all the time, whether someone else is there watching or not. [...] I think conscience is about the small things; the seemingly small things. The things that no one's going to know if you do or not, other than you. (I6 00:34:15)

For this team member, conscience functioned as a check on her own behaviour to ensure that she acted in accordance with her own judgments about right and wrong. For another participant, the

conscientious provision of care involved a feeling of responsibility and constantly questioning, “Am I seeing everything right? Am I missing something?” (I11 00:41:57). Another team member also described the reflective nature of conscience and shared a situation in which conscience had played a key role in her deliberations:

I know that we've had a case with a younger individual who [we were] never really sure if she was completely cognitively intact, and spent a lot of time sleeping during the day, and questions about drug use. And a lot of different family dynamics and a lot involved with younger children. There definitely are cases that you always look back on and wonder if something could have been done a little bit differently, or could we have served that individual better? And sometimes, I don't know that we ever have the clear-cut answer to that. (I2 00:26:36)

This same participant further tied the team’s conscientious care to self-reflection and self-awareness. She emphasized that often determining the best course of action for a patient is itself a judgment of conscience, saying,

My background is very much a feminist perspective - that we bring the best of who we are to the work that we do, recognizing that this is people's lives and this is not about us. But having some sort of awareness about what our belief systems are, what our values are. And I do believe that everyone on the team has a sense of trying to struggle with doing the best possible, so that there's no question in my mind that if there was an issue or a concern that it would be done from a place of - I think good intentions are always paramount and wanting to see the person for who they are. So, I would say that that's a part of all the decisions - in a way. Like, how do you give the best care? Best in some ways is a judgement call, too right? And that it's not always black and white, so how do you find the best possible situations and sometimes, maybe, just because there is the struggle you know that there's a trying to find what that best is. (I2 00:47:22)

These sentiments were expressed by another participant who linked self-awareness with a conscious commitment to providing excellent care:

I think knowing where you yourself are at and knowing your belief system - and not putting that on your patient or fellow team member - but knowing that. And being aware of some of those things in your head [...] that maybe aren't so great - that maybe you know you are going to think that thought, or you know you're going to say, "oh gosh, not that again!" or "he's doing it again!" or whatever it is - but consciously setting it aside in your head and thinking, "okay, well that's okay. Let's set that aside and carry on with caring for that patient the best that you can no matter what. (I3 00:47:42)

It is interesting that rather than treating their consciences as an obstacle to be overcome, the participants quoted here seemed to view their conscience as a positive tool that encouraged self-reflection and improved patient care.

In addition to being described as the root of team members' commitment to caring for patients, in its third facet, conscience was described as actively helping team members to navigate challenging situations ((I8 00:46:48; I9 01:04:29; I11 00:59:59). Participants stressed that their success in these situations was not just because they were good people, but that, as one participant stated, "there is all the skill set, and experience, and the assessment and those other pieces, but it is guided or at least within the context of [conscience]" (I2 00:00:49). During the focus group, this team member further explained that determining right from wrong was more than a gut feeling. She described the active, deliberative role of conscience, saying,

I do think sometimes with [my profession] there's a perception that a [member of my profession] is just a good person and not that there's any thought behind it. Or - necessarily skill. Like someone once said to me, "oh you're such a nice person," as if that was it. Versus there's being sort of a thought process - like, conscious thought [that led to my] questions. [...] conscience as far as thought piece too - when you're doing the right thing, to look at what the ethical framework would be. I think maybe subconsciously there is a thinking through what is the right or the wrong - or the discussion piece - with that. So not always just what feels good or what feels like it's the right part intuitively, but also a trying to think through problems on an intellectual level - the conscious part. (FG I2 00:24:35)

The role of conscience in ethical discernment was described by a participant who shared her deliberative processes regarding patients with potential drug abuse problems. This participant focused more on the balance between giving patients what they wanted and using clinical judgement as she described one situation in particular:

There's certain things that lead the team to wonder if [a patient's] opioid use is either genuine, or if they're using more than they were - there's different things that make you worry. It is about, again, negotiating with the patient a way of meeting their needs in a way that feels safe and responsible to me. So things like - I'm picturing a certain patient in my mind who has since died - but he had to go to the pharmacy every week to pick up his prescriptions because I was finding that he was overusing his fast-acting opioids - so I

would only give him a very small amount at a time and he had to go back every week. It was almost getting to the point where I was going to make him go every day. And then he ended up in [the] hospital. So it's about listening to the patient's experience and honouring it, but at the same time being safe and responsible with those medications. (I10 00:35:28)

This participant acknowledged that it was challenging to strike this balance between the patient's experience and her professional obligations and later elaborated on the role of conscience in this process:

[Conscience is] trying to do what's best. And not necessarily in a paternalistic way, because it's not necessarily what I think is best, but that has to come within the confines of my profession. I went to school for a number of years for a reason. And if it was just about what patients wanted and I had to give it to them, then really we should put opioids in a vending machine. So there is a big clinical decision making process going on, but that can be incredibly difficult to navigate given the subjective nature of what we're trying to treat. So it does become difficult. (I10 00:44:39)

Team members' reliance on their consciences to navigate challenging situations was also observed when team members shared the challenges of balancing patient care with the system's demand for flow (FG I2 01:05:23; FG I3 01:03:37). For example, one participant explained that conscience was active in these discussions, saying,

Often [the] conversation [about our lack of hospice] feels like a sour, bitter, finale at the end of the conversation because we're not happy [and] they're not happy. It isn't as if that's our choice for care for them. That is our right or wrong, moral conscience coming in - we're wrestling with that and they're wrestling with this - "it's really not what I wanted." So sometimes there is moral distress that comes from that. (FG I12 01:02:22)

In addition to helping her navigate this situation, this particular participant's conscience also seems to play a role in managing moral distress when "wrestling" with a difficult situation. The theme of navigating difficult situations was again present in another participant's explanation of the team's nuanced decisions related to patient placement. This participant seemed to understand the conscience as a creative tool when navigating such situations, sharing,

I think we do try to - "massage" the system. [...] But you can look at a system rigidly or you can try to make it work the best for patients and their families. So, there have been situations where we would try - someone who has had lots of seizures - to try to wait a time

frame to make sure that we're not just trying to move them like this inanimate object. But wait to see that we think they're stable enough that they can make that move. (I2 00:44:42)

These comments seem to indicate that while conscience played an active role in navigating challenging situations, it also pushed team members to find creative ways to resolve these situations whenever possible and was linked to their disappointment when they failed to do so. In a similar vein, another team members mentioned the role conscience played in navigating the challenges of resource allocation (I5 01:00:06), while yet another focused more on the need to use her conscience to carefully navigate her relationships with patients, ensuring that she did not overstep her bounds (I7 00:51:06). One participant also stated that she valued this “inner compass” conscience because it guided her to determine “whether I'm in it for me or I'm actually in it for the right or the wrong,” which she stated was particularly valuable because the healthcare system can “buffer” people from this kind of self-awareness (FG I12 00:29:02). It may be that this participant felt that her conscience was an important check to ensure that she did not get swept away in her own goals or those of the healthcare system, rather than focusing on her patients.

These three facets of conscience (conscience as the arbiter of right and wrong; conscience as something that motivates the provision of quality care; and conscience as a navigation tool in complex situations) were implicit in the interviews with team members, and they were first articulated to the team during the palliative care focus group (FG M 00:22:30). Conscience was an elusive concept during the focus group’s discussion and was at one point identified as being “subterranean” (FG I12 01:03:30). Although participants stated that their consciences were always present in their decisions, the impact of conscience on the team’s decision making seemed to be difficult to articulate. Despite these difficulties, team members were able to have a fruitful discussion and proposed that the ability to know right from wrong, the drive to work



conscientiously, and the ability to navigate challenging situations were three ways of using the conscience, rather than three separate and distinct faculties (FG I2 00:24:35; FG I6 00:24:18).

One participant explained that she relied on these different facets in different situations, and that they worked best when she collaborated with other team members:

I think I would probably use all three [facets of conscience in] different scenarios too - I think you mentioned on different occasions, and I guess sometimes when things seem very black and white then that's easy. When it isn't, then you need to pull in more information and maybe that's when the consultation might [happen] with another nurse - or another nurse goes out, because sometimes we don't go in as a team. (FG I11 00:27:15)

When asked if the different parts of conscience could be separated, or if “healthcare providers should just leave their consciences at home,” focus group participants responded with a unanimous “no” (FG M 00:31:15). This prompted one team member to say, “if anyone can teach me how to do that, please teach me how to do that because you are in the wrong business if you are working here and that is your thought process” (FG I6 00:31:52), while another stated, “I don't think you'd like to meet me, or to work with me if that's who I became. I think I would be a different person if I had to separate myself out in that way. I think I would show up for work with a totally different suitcase” (FG I12 00:32:14). During their interviews, team members balked at the idea of leaving their conscience at home as well. One participant explained:

[Who you are at work] has to be who you are, through and through. I always believe in getting everything out on the table. I mean you can't always do that with people, but - [for example,] we have a memory tree that we set out at Christmas time. It's in the mall, and we've always done it on work time. And it's never been a big deal, but we're so busy now. So I went to my boss to make sure that she knew we were doing it on work time and she said, "did you always do this?" And I said, "Yes, we have - ever since I've been in there we've done it." "Okay," she said, "just work your hours as good as you can." But for me, I'm a kind of person that I always want to be upfront if I possibly can be because I don't want, three months from now, - this is a small example - but her to come back and say, "why didn't you tell me you were using all these work hours for memory tree?" I want it on the table, so my conscience is clear. I know that's not to do with patients, but that's who I am, so when I come to work - if that was my mother or father, I want to have done the best job I can do for them. Not necessarily, "will it be what my mother or father would have chosen?" but I want to honour their wishes as best as I can. (I7 00:49:09)

It is interesting that in addition to stating that she could not be a different person at work than she was in other parts of her life, this participant also tied her integrity to her commitment to honesty. Similarly, another participant also stressed her need to bring her whole self to her work as a healthcare professional and the impossibility of being two different people:

I think that's partly because I don't feel I can split off who I am from what I do. I know there's a debate about that even in the political realm. Can who you are be totally, radically different than the role that you fulfill? I don't believe you can. I think you're one in the same. So if this is a mess on a personal integrity level, probably this is going to be a mess on a public, professional level. (I12 01:15:51)

In the stories and reflections shared by participants, conscience was upheld as an integral component of the care provided by the members of the palliative care team because it demanded that they bring their best selves to the people in their care.

Perhaps due to its role in maintaining integrity, conscience also played an important role in the relationships both among team members (FG I2 00:26:30) and among team members and patients and families (I3 00:44:12). For example, when asked during the focus group if leaving her conscience at home would be possible, one participant explained that her work could not be accomplished without her conscience because she needed it to form relationships with those in her care. She shared,

I personally think [...] palliative homecare wouldn't exist [if we left our consciences at home] because [patients] have to allow us into their homes, and if we didn't have a relationship with them - if they didn't have a sense that we could do something for them other than give them a pill - it's journeying with them. And if they felt we were a robot - which is I think what that would be - that we wouldn't have a purpose in there and I don't think palliative homecare would [exist] - because I think it's about relationship. It's about journeying with them and that they know we care. We can't change the journey [...]; we can just journey with them. And if they don't see us as caring people, they'll just decline every visit. And that's their choice to do it. (FG I11 00:33:28)

While this participant implicitly connected her conscience with her ability to form relationships with her patients and care for them, another participant made a more explicit connection between

persons who have their consciences engaged and persons who provide excellent care. This participant stated, “I guess I just don’t know very many people who are absolutely neutral and have a deep, passionate, caring, personality” (FG I12 00:34:13). Similarly, another participant connected conscience with self-awareness and stressed that both were necessary to care for patients:

I think if we miss knowing who we are in the work that we do, and if we miss knowing who individuals are other than their diagnosis, we do huge disservice to the people that we work with it. [...] My personal belief is that you cannot - I don't believe that anyone is totally neutral. I think that if you know yourself and you know how you are in relationship so that its always to the benefit of the patient. So that when we're in relationship, the things we choose to share are things that maybe benefit the patient or the relationship, if that makes sense. It's not an inappropriate relationship. It's still a very professional relationship that is geared towards what is in the best interests of the patients or the families that we're working with. (FG I2 00:32:32)

This participant seemed to suggest that self-awareness was a necessary tool for healthcare professionals to form relationships that were authentic while continuing to be professional. I interpret her explanation as further evidence that the formation of healthy healthcare professional-patient relationships was seen as dependent on conscience. Healthcare professionals who are able to bring their authentic selves to these relationships did so because they were aware of their own strengths, weaknesses and biases, and used their consciences to determine which parts of themselves should be shared with those in their care. This same team member shared the advantages of conscientious behaviour, as she stated that patients seemed to feel cared for when they received attention from team members that went beyond the provision of basic physical care:

I think one of the pieces was a family had written a thank you note to the palliative care unit and just the kindness that she had experienced. And the example was that one of the nurses had found a little silk pillow to put behind her mom's ear, so for me it's not necessarily the big things but some of the attention to the smaller pieces. And just having conversations, getting to know who people are and what's important to them that I think [leads to] success. And not to say that we're perfect and that every situation goes

completely smoothly because that would be an error. We do have our struggles, and we have the patients that challenge us more than others. My hope is that when things don't go well, we each try to look back to say, "what could I have done differently?" Try to look at that piece. So I think reflection is a big piece of that. (I2 00:00:53:53)

While this story places an emphasis on self-reflection and the role of conscience in prompting team members to form authentic relationships with their patients, another participant also placed considerable importance on conscience as a faculty that connects human beings. She explained that palliative care is often the bearer of this form of conscience, saying:

Often I think [the palliative care team comes into other units] as the conscience. [.....] Say in long-term care - we come in for physicians at the end of life and define what that is - what end-of-life care is - and that is according to what our philosophy is, right? So often times we'll come into long-term care and start discontinuing medications. And that only comes from not wanting our patients to suffer because of pill burden or taking medications that don't make any sense. So I think really in this job your conscience guides you. What's right and wrong? How would you want to end the rest of your life? And can you make that happen for other people? What we decide as humans - as far as comfort goes - I think is often agreed on. And that's just because of being human. I think what you're asking is - really if you take it right down to it - you're asking about the theory of humanism. And that is: our need to be able to provide good supportive care to other human beings. So [conscience] guides us, you bet. I think that it does. I think that you as a human being are going to have emotions about other people's distress - whether that's physical or emotional. And we're guided to fix that or to make that better. And then moral distress comes when we don't get there. (I9 01:04:29)

Here again conscience was described as an asset that actively helps the palliative care team to navigate complex situations and establish relationships with those in their care.

As can be seen, it was challenging to discuss conscience directly because team members were not accustomed to teasing out their moral judgments from their other deliberative processes. However, team members shared many stories that implicitly revealed the aspects of the role of conscience in their work as something that helped them to determine right from wrong, provide quality care to their patients, navigate challenging ethical situations, maintain their own integrity, and establish authentic relationships with those in their care. The following

subsection provides findings and further detailed accounts in which the consciences of team members were implicitly part of their deliberative processes.

### **Conscience at Work: Stories of Ethical Dilemmas in Palliative Care**

The three facets of conscience and their role in the palliative care team's relationships can best be seen in the stories that participants shared about times when they faced moral distress. Although participants were provided with a definition of moral distress that stated it occurred when "one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Andrew Jameton as quoted in Burston and Tuckett 2012)), many participants went beyond this definition when sharing morally challenging situations. These situations covered a range of challenges, including patient placement, terminal sedation, caring for patients with drug addictions, and physician-assisted death. In this section I present some of these stories to highlight the role of conscience in the deliberative processes of palliative care team members.

As already noted, patient placement was a recurring theme in many of the stories shared in this study (I8 00:33:19; I10 00:34:20). One participant clearly outlined this particular set of challenges, explaining that the patient placement system focused on a patients' physical health, with little regard for their psychosocial situations. She provided examples, saying,

There are situations where [nursing homes are not] really set up to support couples - so people who've been married for fifty, forty, sixty years, and require a nursing home - that they have to be apart. [...] Sometimes I think the system is looking [for] the right care at the right time, but what it means is trying to move people as quickly as possible. And I think that would cause me more moral distress if I didn't - for example, policy right now is, I think, they're sending people in long term care to [a small town outside the City]. But our physicians said, "no, we're not going to - we'll take them off the list if we have to send [them away]" Because we have one individual now who nursing homes won't take, probably because of his addictions. He has a parent who comes to visit him on a daily basis, but comes on the bus, so would not be able to see him if he was [outside the City]. And we have had other people who - elderly - would not be able to make that trip, so that our team will say that we're not doing that. Whereas on the wards, sometimes there's a big

push to get people out. And so, sometimes it's just trying to figure out how you can make sense of that piece, and not always listening to exactly what the system tells you to do. (I2 00:41:46)

In this story, it seems that the team members' consciences alerted them to the injustice of sending a dying patient away from their family and compelled them to find a better solution for the patient, even if it meant finding creative ways to work around the system. Similarly, another participant shared her moral judgments concerning patient placement, particularly for patients who were near the end of life and required a palliative care bed:

One of the things that I found really bothers me, is when we have our patients getting admitted to emerg, and they die down there. They don't even get up to a bed. I think there are just some really big issues around that. So the whole bed thing is certainly an issue for us. Not having beds on the palliative care unit [.....] - it used to drive me crazy when I was up on the unit - we'd have people waiting for long-term care, and then we'd have other people who desperately needed to come in for symptom management. They couldn't come because we didn't have a bed. We've got a guy on our unit right now who has been there for six months - he doesn't need to be there! So that would be the institutional piece that is really, really frustrating. (I5 00:47:05)

While this story provided insight into the participant's distress on a professional level, a different participant shared an emotional story about a situation that had touched her conscience on a personal level when she felt the system had prevented her and her team members from following through on their ethical judgments regarding a patient's care:

This lady was dying - not on palliative care. And the family decided that she would be a DNR and her husband wasn't doing well also. [...] They had been together - I don't know how many years it was - I think it was 60 plus. And then all of a sudden he was slinking down in his chair, he was unresponsive, the whole nine yards. [...] Then they assessed him downstairs, and the family decided he would be a DNR. My moral [distress] was: [*tearfully*] why couldn't they have him in the same room. Why couldn't they be side by side. Because here his wife is dying. Here he might be too. Why, you know, because, [*mimicking*] "you can't do that! That's the rules!" Honestly. I had such a hard time with that one. I couldn't believe it. Sorry, but - even if they could have put him next door, that would have been better than the family going in between one department and the other. Oh it was horrible. I really felt for that family. That was not right. Inside of me felt that was not right. (I1 00:57:32)

I understand this participant's statement "inside of me felt that was not right" to be a clear expression that her conscience was active in this situation, and it seems that her moral distress was caused because she could not act in accordance with her judgment of conscience. As another example of moral distress, a different participant shared a painful story in which, despite having spent hours on the phone, she was unable to help her patient get back home:

I had a patient who, and again, this didn't happen on palliative care, but this was a palliative followed patient, if that makes any sense. He came from a palliative unit in a different town in [the province]. Anyway, they felt they couldn't manage him there, and they wanted to send him for some procedure or test here to decide how they could manage him better in the town where he was from. So they sent him here via ambulance one night, and this man was [.....] young. And the next day when it was very clear - I mean this man was very, very, very sick - the next morning when I came on shift it was very clear that there was really nothing other than comfort measure that we could do for this man and he wanted nothing more than to go home. That day he wanted to go back to - not home, he wanted to go back to his home town. This is first thing in the morning when I get on shift. I'm going to do everything in my power to get this man home. [.....] So this man had three kids there and his wife [.....]. It ends up being just one delay after the next. [.....] So the ambulance in his home town is busy, then they broke down, then they went for lunch before they got here. And it ends up being four o'clock in the afternoon and the man dies. And I could not get him home on that day. [.....] That's my moral distress. (I6 00:20:44)

In this team member's story, conscience seems to have helped her identify the wrongness of preventing a man from dying at home and spurred her to try many creative solutions to achieve her patient's goal. Yet another participant shared a challenging experience in which palliative homecare was almost forced to take a patient they did not feel they had the resources to care for:

Somebody who was very sick in [another part of the hospital] - we got an order that they were going to be sent home [.....] and we could care for them, and they would probably die in a few hours. And I was very distressed. I said, "you've got to stop the bus here because - are they going to have drugs? What happens if they live? You need to [keep them] in the hospital and see what happens. Anyway, we got [a palliative care doctor] involved and he went over and talked to them, and [the patient remained in the hospital]. I was feeling a lot of distress over this - and how do we handle it? [The hospital staff] didn't seem to have a clear picture. I said, "we're going to be in the home for 45 minutes. We don't stay in the home. We don't have the time and we don't have the nursing staff. Who's going to take care of this person if they live for 24 hours? Where are the drugs going to be? Where are the orders?" There were so many factors. In the end, they didn't send [the patient] home. [.....] But yes, I was very distressed, but it got stopped [...]. And because we do work closely

with our doctors, I brought it up to [our palliative care physician], and said, "I've never been faced with this. I don't know where to go with this, but we cannot cope with this in the community." And he said, "I'll talk to them." And it got stopped. (I7 00:36:01)

I observed that in addition to her judgment that bringing a patient home who could not be cared for is unethical, this participant's conscience also compelled her to reach out to other team members for help in resolving the situation. In each of these stories, staff members related that they were aware of failures in patient care, and although a positive resolution was not always possible, the participants felt compelled to find ways to help their patients overcome the constraints of the patient placement system. Although the word 'conscience' was not used in these stories, I intuited that this faculty was implicit in participants' accounts of their deliberative processes regarding patient placement.

In addition to situations involving patient placement, I also observed the active consciences of several other team members in their stories about patients and families who did not understand the severity of their disease or their treatment options. For example, one participant reflected on the team's collaborative approach to a patient and family who refused to discuss the patient's terminal illness:

I like to ask myself - and I ask my coworkers and my manger - "is there something I should have done differently? Should we have done something differently?" And I think sometimes what we do in situations like that - even though you asked me am I the only one that goes into a situation like that - when it's something like that, we actually adjust that and maybe more than one nurse will go. So that we can have two different eyes [and] thoughts on what to do in a situation like that because [the other nurse and I] were both feeling the same way [...]. But at least you're not doing it alone and at least [I know] it's not [just] me. And [I get] maybe a different angle or a different way of connecting with someone. Those are hard. Those are very hard situations because you kind of see it coming and you just don't feel good about helping them see it coming - and then it's much more of a shock and a surprise. A shock. [Some patients are able to] say all the things [they want] to say to family [in the last couple months] - [this person] wasn't able to say all those things because the client - they didn't have those kinds of conversations. [...] It was much more tension. The reality is there's lots of family dynamics that we can't change. We walk into them and there's lots we can't change because they've been like that for years. (I11 00:30:02)



I observed that this participant's conscience was active in the questions she posed to herself, prompting her to collaborate with her team and helping her to navigate a situation that could not be clearly judged as right or wrong. Similarly, another participant explained the challenges involved in caring for patients who did not have a clear understanding of resuscitation, highlighting the need for clear communication in these ethically sensitive situations:

On the oncology unit, I saw so many [beyond reasonable or faint hope] resuscitations. And what the patient and families don't know is that the medical team attempting the resuscitation are the ones who want to give space for those last moments of life to be with family. At the end of the palliative illness, a 'CODE Blue' with all the rush and adrenaline and physical interventions will not change the journey. It will only make the final moments of dying that of technology rather than quiet comfort and presence by family and staff. Just like with fluids or food, the dying person is not going to wake up to better stronger health. They're going to wake up to the same as where they are right now. But families just know only TV medicine. It is such a dupe that our media culture has placed on the average individual. We don't know death - the vast majority of people have never been with someone - have never even been with a grandparent as they've gotten closer to death - because we have this bizarre little phrase that, "well, I want to remember them as they were," as if somehow they've already gone away. [.....] Just because they're frail and gaunt and maybe don't make the same clear sense they still need our love and caring presence - that again is speaking to our value though on what we as a society tolerate and how we deal with suffering. (I12 00:38:43)

In addition to helping this participant frame her judgments about how the final moments of life ought to be for her patients, this participant's conscience seemed to be present in her reflections on honesty, which interestingly brought a moral dimension to the way this participant spoke about death with her patients. In her descriptions, these conversations seem to be a moral requirement for her, not simply a routine part of her job. Managing the expectations and goals of patients proved to be a recurring theme for team members, as another participant shared the story of a patient who had misunderstood the proper use of terminal sedation in end-of-life care:

[The patient] wasn't in physical pain or [experiencing] shortness of breath - it wasn't any of the physical things - it was for suffering. And when we tried to explore that further with her to try and figure out - well, obviously she had reason to be suffering, she was dying from a terminal illness - but trying to delve deeper into that and trying to figure out has she

tried [and] have we as a healthcare team tried everything we can to try to lessen that suffering. Because terminal or palliative sedation is kind of your last thing, right? So we always try to figure out, "have we tried everything else up to that point?" And she wouldn't let [us] - she said, "oh yeah I've seen a psychiatrist and I've done everything that I should be doing to try to fix this, and it's not fixable so therefore you can sedate me." And she wouldn't give us the psychiatrist's name, she wouldn't tell us details surrounding the care that she had tried to get, surrounding her spiritual suffering. So it was really difficult. (I3 00:19:13)

This participant explained that the team's concerns about the patient's desire for terminal sedation were connected to their commitment to provide her with holistic care and to examine the psychosocial reasons for her suffering, sharing,

Some of the details I can't remember, I just remember that a lot of times her husband spoke for her, and that we tried to talk to her about - that she wasn't physically going to die within a short time and trying to help her - could she live while she was dying, so to speak? And she didn't want any of that; she just wanted this terminal sedation. It was really difficult because morally and ethically, yes we can use terminal sedation, but you have to be sure, first of all, that you have tried to help this patient with whatever symptom they're dealing with, with all modalities. And they have to be truly right at the end of life. Because when you sedate somebody, if you sedate them into deep sedation, they won't eat or drink anymore. And, so if they're not at that point within their journey, that they wouldn't be eating or drinking anyway, then essentially they're starving to death. So you can't sedate them at that point. And that's exactly where she was. She was up walking! She wasn't anywhere near that very end of life. So we met as a team many times. The nurses were actually paid to come in on their day off. We had the ethicist involved, obviously, in it, the manager, as many people as we could to try to figure this out. We involved that initial doctor that supposedly had told her she could get the sedation. [...] It was just hard to wrap our heads around that one. (I3 00:19:13)

In this story, I observed the consciences of team members actively trying to form a judgment about what to do to care for their patient. For example, the participant shared her concerns over the patient's husband and described her attempts to understand her patient's motivations. She also described her own uneasiness and her appeal to other team members to help her navigate the best course of action, all of which I interpret to be the product of her active conscience. While conscience was implicit in the team's deliberations in this story, another participant stated that her conscience helped her to navigate the challenges of terminal sedation:

I think where [my conscience] might raise it's head a little right now for me in palliative medicine is just that fine line with palliative sedation and conscience coming into play - "who am I actually treating here?" Because the distress of the family can be so great - so I want to make sure that I'm always treating the patient - what their wishes are. I've never felt that it's a really tricky line for me to manoeuvre in the medicine that I practice. (I12 01:06:26)

I observe in these stories that palliative care team members relied on their consciences to help them navigate situations where a patient or family's understanding of their disease and treatment options was limited or complicated by social circumstances that made it difficult to form a black and white moral judgment. In these situations, participants relied on their team members and honest communication with patients and families to clearly establish the goals of care.

Several participants related the challenges of caring for persons with drug addictions (I3 00:44:12). For example, one participant shared the team's thought processes and commitment to providing non-judgemental care for one patient in particular:

We have [...] a gentleman who has drug use [challenges]. So, we've had conversations about, "is it important for him to die without drugs?" [We've] had conversations about linking him up with Addictions Services. He has a nice, wonderful, sweet parent who comes to visit on a regular basis. So, we try to make it the safest for staff. And maybe just accept that this is who this person is, and try to approach it with non-judgemental care. Not keep a blind eye to it, because we need to make sure that everyone who cares for him is safe. (I2 00:31:58)

Conscience seemed present in this participant's efforts to balance respecting her patient's wishes and the safety of caregivers. Her conscience was active in her attempts to involve healthcare professionals from Addictions Services with this patient's care as this seemed to be an attempt to resolve the situation in a manner that minimized moral distress. The challenges of caring for persons with drug addictions were also evident as a different participant related the importance of trusting her own moral judgment. She shared,

I think one of the hardest groups that I've found over the years to deal with are people [who] are addicted to pain medication. So there's really a huge, huge push to prescribe more and more and more and more. And I know that's not appropriate, but it can get really

dirty with the patient, family, everybody. And often the institutional piece in that would be called [to] do more, do more do more - you need to do more. And the nurses will be bothered because they're being called in the middle of the night by the patient or the family - everybody is very distressed. So there's just this kind of attitude of, "you should fix this. You should be able to fix this and you're not fixing it." When there are situations that can't be fixed. So often - there have been quite a few cases - where we just said, "we cannot fix this. This is not fixable." It's not fixable by usual avenues. So I don't know if you'd call that institutional, but there certainly can be a push to do something that doesn't feel quite right. (I5 00:47:05)

In these comments, I observe that this participant's judgments of conscience provided her with insights to clearly communicate her reasons for being cautious with her provision of drugs for this particular patient. Another participant described similar situations and by doing so again demonstrated the self-awareness of team members when providing non-judgmental care:

We've had a few patients lately who are drug addicts. And, I know that's a disease, I know that's an illness, I know they don't want to be addicted to medication - they don't! And it's not a lifestyle that anybody would pick for themselves. And I know all that inherently but sometimes I have to really talk to myself - I don't know if this is moral distress, but for me it is personally - I just really have to keep telling myself that they can't help this. (I3 00:38:02)

I observe that in addition to compelling her to examine her attitudes and beliefs, this participant's conscience compelled her to act on the moral judgment that all her patients are deserving of care. Throughout their interviews, participants also reflected on the challenges of caring for patients who continue to smoke while on oxygen (I3 00:38:02) or for families who fail to follow isolation protocols (I3 00:27:49). In each of these situations, conscience was implicit as a tool used by team members to find a balance between the autonomy of patients and families and the safety of everyone on the palliative care unit. As I have indicated in my observations, participants' descriptions of their deliberative processes revealed that conscience was a key tool for healthcare professionals who aspired to provide non-judgmental care even in ethically challenging situations.

It is worth noting that the interviews and focus group with the members of the palliative care team were conducted only a few months after the Supreme Court of Canada's landmark Carter decision (2015), which struck down the Criminal Code prohibitions against euthanasia and assisted suicide. Although at the time of their interviews the Carter decision had not yet come into effect, several palliative care team members highlighted the unique challenges of caring for patients who might request physician-assisted death, which was the predominant term used for these practices throughout the interviews (I11 00:54:20). In her interview, one participant clarified that palliative care does not "do anything to hasten death or to prolong it, but just to be with people and try to hold that space with them and to make them as comfortable as possible while they're here" (I2 00:34:43). Given the deeply personal nature of physician-assisted death, the team's stories about this topic were particularly effective at showing how their consciences compelled them to provide holistic care. For example, one participant shared a story about a woman who had inquired about euthanasia and the value of clear and honest communication:

There was one other lady, and she asked me awhile back if euthanasia could happen, and at that point I said, "no, it's not legal." Pursuing why and what she was going through, her thought was that she was going to try and spare her children anything more because she knew she was dying. She was going to try and spare her children. And she ended up on the palliative care unit and her children came to her - the families came to her - and she died a fairly comfortable death on the unit. Her intent was to save her children anguish, when in reality they needed the time to be with her and to face it. To take away that time from when she said it [to when she died] - if she would have made it happen - they needed this time in here. They desperately needed this time to be around her, [but] she was trying to be a mother [and] protect her children. I think once we talked through it, it didn't get brought up again. It helped me understand and think about more what her motive was. She wanted to protect her children from seeing her suffer, but that was part of what they needed to go through - she was holding them off a little bit [...] Anyway, that was good. (I11 00:50:36)

It is interesting that rather than abandoning her patient, this team member's conscience seemed to have spurred her to tend to her patient's psychosocial needs. Similarly, a physician shared

both her frustration regarding physician-assisted death and her commitment to communicating with her patients:

Well I think what it is - is the demanding-ness of the public to have the physician then become -not a physician - a technician - and I'm [...] opposed to that. I didn't go into medicine to become a technician. I could pick any number of careers that that would have been the case. [I hope to be a healer of persons.] But again, I don't want to be a dictator either - I think that finessing conversation with, "tell me more about why you're requesting this," is much more valuable than having a rigidity that doesn't allow conversation. (I12 01:06:26)

This team member's comments provide insight regarding the ethical weight she places on maintaining respectful relationships with those in her care. It may be that her conscience not only provides her with the judgments she needs to navigate challenging end-of-life issues, it also compels her to actively listen to the concerns of her patients. These comments and the other stories shared on this subject provide evidence that palliative care team members viewed requests for physician-assisted death as an indication that the team needed to further explore their patients' physical and psychosocial needs. It is unclear whether this will still be the case now that this practice is legalized.

Many of the stories in the preceding paragraphs heighten participants' use of conscience as a decision-making tool in patient care; however, conscience also played a major role in team members' desire to improve the healthcare system. For example, one participant related:

I think distress comes for me morally [because] our system is intent on ignoring the needs of the dying [...] That our resources for palliative care are so low in comparison to the monies that we spend in all other ways. And I actually take that on probably as a bit of moral distress - and that would be a lack of control again. That there are so many things that we would like to do better in palliative - there are so many programs that if our team were involved I know it would make a wonderful difference for patients and families. So I would say that would be more where I would experience moral distress. (I12 00:48:40)

For this participant, moral distress seemed to be a message from her conscience that something was not right with the system and that she should act to change it. Another participant expressed frustration at the wasted resources that could be better spent elsewhere, stating:

One of the issues for me is this whole TPN business. So here we are, we're giving people who really are very much at the end of life a futile treatment. So when we're giving futile treatments, I have a real issue with that. And expensive futile treatments. TPN is really, really expensive - hundreds of dollars a day. People will often be on this for weeks or months, and I just cannot - and I've been certainly asked about that - "Can so and so get this?" If it's up to me I just say: "there's no evidence that that will prolong life in any way - it might shorten it. So I am not prepared to do that." [.....] I think the huge cost of healthcare and giving futile treatments, that really bothers me. And the chemo therapy that would cost that much, that would have very, very, very minimal chances of success - [....] this is not for the best. (I5 00:31:58)

Here again I observe that the participant had formed a negative moral judgment about healthcare practices and felt compelled to act in a way that would improve the system by avoiding unnecessary procedures. As seen in these statements, the moral decision-making of team members impacted the health region beyond the confines of palliative care services, motivating conscientious healthcare professionals to improve the whole healthcare system.

When faced with morally challenging situations that required a fully engaged conscience, palliative care team members used a variety of tools to alleviate their moral distress. Many of these tools were highlighted in the section on team collaboration in the previous chapter, but it is worth returning to these in order to address their role in moral decision-making. The moral dimension of the situations mentioned in this section required some team members to rely on their spirituality (I11 00:59:59; I12 00:50:36), while others focused more explicitly on their role in facilitating patient choice. As one team member explained:

It is hard. It is hard, but again [...] the way I think about it, myself, is to try to do my best job getting the information I can to the patients and families. And ultimately this is their experience, not mine. And so if they want more investigations and more treatments that are causing suffering - absolutely that's hard to watch - but on some level they're choosing that for a reason because it meets some sort of need - usually a psychological need - [so] they

would need to keep intervening and keep trying. Because that hope is still there. I think I sometimes need to force myself to remember it is about their choices and as long as I've done my job: supporting them in making those choices and informing them of the pros and cons, then it's out of my hands. (I10 00:25:51)

Through this participant's comments, I observe that she felt compelled to provide respectful care for her patients and that her conscience played an active role in determining what constituted an appropriate amount of responsibility for her patients' choices. While this participant's comments focused on her relationship with her patient, many team members identified their colleagues as a source of great support, describing the team as having provided a safe and supportive environment in which to speak up when something was troubling them (I3 00:47:42; I8 00:34:14). One team member related the value she placed on her colleagues' advice:

[I] trust them that they're going to say - because they have said to me, "okay, listen, you need to chill out here a little bit," or "you need to not get so worked up about that problem or that issue that you can't do anything about. So there's no sense losing sleep; there's no sense getting angry, because you can't do anything about that thing. So let's move on." And that's part of their conscience, knowing that as a team we have to stay healthy, and to stay healthy you have to be able to say to each other, "hey listen, you need to take a minute." [...] So to me, that's part, I think, of how it functions so well. (I3 00:49:06)

Many team members explained that talking through a problem often led to a "better understanding" of the situation (FG I11 00:28:43), with one participant sharing,

Yeah, and we'll talk - sometimes it's us that has the moral distress. "I don't understand what this family [is] doing. This is not proper or right in my head about how to treat your family member." And we'll bounce those things off. I mean I'm not going to be able to solve that - I still have to work with those people, but just to let your other teammates know that you're slightly uncomfortable with this, and you may not be the best team member right now and maybe they need to take the lead. Or we've had situations where the family have gotten upset about something that our physicians have presented or a medication that's been ordered, and then I'll take the lead and have the physician visit less - that sort of thing. So we sort of bounce things off of each other. (I9 00:38:06)

Still others expressed the value of ensuring that all team members were on the same page and the importance of discussing any moral objections before approaching a family (I3 00:32:41). As



described by participants, engaged consciences need a number of support mechanisms to continue to support the relationships that are required to provide holistic care.

Each of the stories compiled in this dissertation provided insight into the functioning of conscience in the members of the palliative care team, drawing attention at various times to each of conscience's three facets. First, conscience frequently alerted team members to the rightness or wrongness of a situation, particularly when patients were not being treated justly by the healthcare system. Second, participants also related that their consciences spurred them to action and the provision of conscientious care, particularly in situations where patients could not advocate for their own needs. Finally, conscience was observed as a navigation tool in situations where the right course of action was unclear, such as when the principles of autonomy and safety needed to be balanced. Although at times one of these facets of conscience can be distinguished from the others, the stories told by participants reinforced the team members' assertion that the three facets cannot be easily separated. Identifying ethically challenging situation, taking action, and exploring the nuances of how to act were often all the same process, and each stage required the full engagement of conscience. I also observed that these processes were reinforced by the other themes explored in this chapter: clear communication ensured that the values, goals, and moral judgments of team members and those in their care were understood; team collaboration provided individual team members with the insights of multiple perspectives; and the team's commitment to holistic care seemed to orient team members towards their relationships with their patients. Far from operating in isolation or hindering patient care, the consciences of palliative care team members were present to both their teammates and those in their care, ensuring that patients received exceptional care.

As can be seen in this section, the palliative care team considered their consciences to be an asset as they navigated through ethically challenging situations. The team members' stories of moral distress implicitly showed that, when fully engaged, their consciences had provided them with an awareness of their patients' emotional distress and spurred them to resolve these situations in any way possible. Further, intact and engaged consciences were seen to be working in tandem with the other four themes mentioned in this and the previous chapter: clear communication, the collaborative team approach, holistic care, and real relationships. The interconnectedness of these themes will be further discussed in Chapter Six.

### **Summary**

This chapter has presented the second part of the findings gained during the first phase of data collection of this study. In this phase, I analyzed the transcripts of eleven interviews and a focus group with members of the SHR's palliative care team. During my analysis, five themes for the deliberative processes of palliative care emerged: clear communication, a collaborative team approach, holistic care, real relationships, and engaged consciences. The previous chapter addressed the first three of these themes, while this chapter provided evidence to support real relationships and engaged consciences. These final two themes were implicitly present throughout the stories shared by participants, who generally only made direct statements on these themes when prompted to do so. Participants indicated that they needed to form authentic relationships with their patients to provide holistic care, and further analysis and focus group discussion revealed that their consciences were actively engaged in these relationships. In the following chapter, I provide a more complete analysis of the connections between these five themes and present the findings from the two interpretive panels that commented on whether the

deliberative processes used by palliative could inform policy and practices in other areas of the healthcare system.

## **Chapter Six:**

### **Interpretive Panels Findings**

#### **Introduction**

The first three chapters of this dissertation outlined the purpose of my research, related literature on the topic of conscience, and the methods of this study. As outlined in Chapter Three, the data of this study were gathered to provide findings for each of four research questions. In Chapters Four and Five, I presented the findings from the interviews and focus group with the Saskatoon Health Region's palliative care team. In this chapter I provide an analysis of the relationship between the five themes that emerged during my analysis of the data collected from the palliative care team, and I will present an analysis from the data collected from the two interpretive panels. I use both sets of findings to answer the research questions in the context of the related literature in Chapter Seven.

#### **A. Analysis of the Five Themes of the Deliberative Processes of Palliative Care**

The preceding chapter presented the findings of the interviews and focus group conducted with eleven members of the palliative care team who were intentionally selected to represent a diversity of healthcare professionals. In these sessions, five themes emerged by which palliative care tools might be categorized: clear communication, collaborative teamwork, a holistic approach to care, real relationships, and engaged consciences. In Chapters Four and Five, I presented these five themes in order, from the most to the least easily observed theme. Although this presentation suggests that these themes can be understood individually, in the stories shared by the palliative care team members these five themes appeared to be inextricably intertwined. Given this complex relationship among the five themes, it is also useful to explore

them through an analogy. The referencing system used in Chapters Four and Five will continue to be used.

In Figure 6.1, I have presented the five themes in the form of a tree. In this picture, the flourishing branches depict holistic care as the primary goal of the team. The tree trunk represents the real relationships team members were able to form with each other and with those for whom they care, which supported the provision of holistic care. These relationships were in turn rooted in the team members' authentic selves, which includes their engaged consciences. Although the conscience was subterranean (i.e., often difficult to observe), it remained engaged with team members, patients, and families and appeared to be needed to nourish the relationships that supported the provision of holistic care. Taking this analogy further, if holistic care, real relationships, and engaged consciences are the parts of the tree, then clear communication and a collaborative team approach may be best understood as external tools that are at the service of the tree. In figure 5.1, clear communication and a collaborative team approach are depicted as a ladder and an orchard worker respectively, emphasizing that the tools present in these two themes are only valuable when they are used to prune the tree (i.e., to further the goal of providing holistic care).

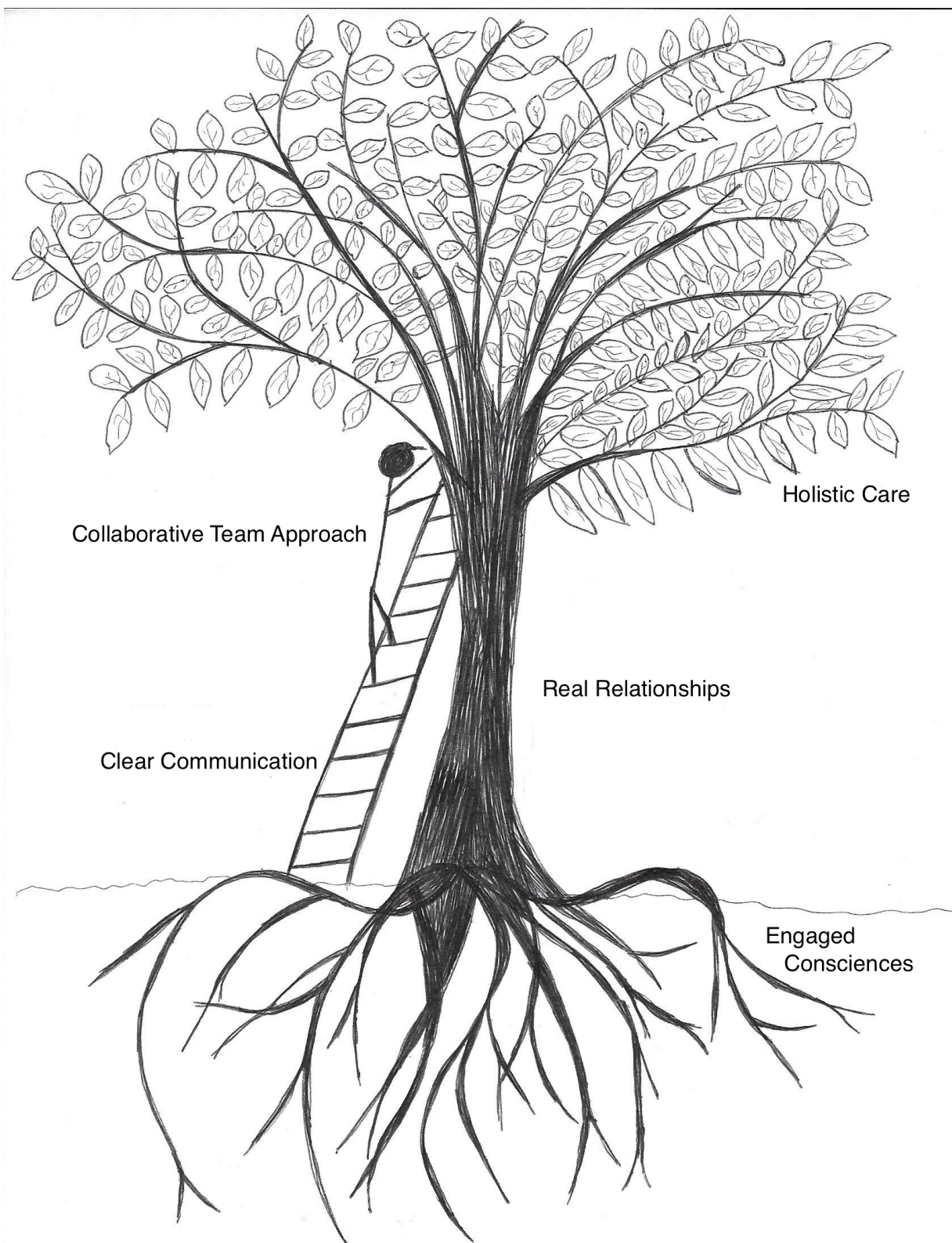


Figure 6.1: Analogical Representation of the Five Themes

To further explain the relationships amongst these five themes, I will consider a story shared by a palliative care team member. In this story, the participant was called to visit a patient who was not on the palliative care unit and was nearing the end of her life. The participant shared,

Our success stories always have happy and sad endings. Because usually the stories that I think about that are success stories for me in my work are always patients dying where they want to die - but they still die. So I guess I'm thinking about that lady that I was telling you about a minute ago, who was on the BiPAP, who got sick quite quickly. And the nurse coordinator who I work with was involved in the case a bit earlier on in the day, and when she first got called in, the family and the patient disagreed about the course of treatment. There were some antibiotics that another member of the [non-palliative care] team said would make a big difference to this patient, but the patient was unfortunately too sick to benefit from them. So then the family was very agitated - this woman's children were just desperate to help their mom however they could, and that was causing a lot of friction between the kids and the patient - you add in the husband, who was a second husband, not the kids' father - then you add in the healthcare team who was sending mixed messages to the patient. There was a lot of friction that I've heard about - luckily a lot of that got sorted out [by the nurse I work with] before I walked in - just the luck of the timing of it. Ultimately the patient did not want a lot of aggressive interventions. The patient herself was one of the few people in the room that knew how sick she was and where this was going. And so, again, it was just we took the time to talk with the family; we took the time to listen to the patient - and she told us. And in the end - later on that day - we ended up sedating her and taking the BiPAP mask off. And she died about an hour later. It was a difficult day of negotiations and explanations - going away and giving the family space - and coming back. But in the end she died surrounded by her family who came to support her decision. And she died comfortably. And that was powerful. It was beautiful. (110 00:51:37)

In this story, clear communication was the most observable theme as the participant described her clear statement that antibiotics would not benefit the patient. The participant's skills as a communicator were coupled with her collaborative approach to team work when she described the time she and her colleague had spent with the family to explain the treatment options. Although the team member telling the story was not present throughout the day, she benefitted from her colleague's commitment to forming a connection with this family throughout "a difficult day of negotiations and explanations." This commitment to the family is evidence of the

value the palliative care team places on forming real relationships with those in their care, which is further demonstrated by the storyteller's knowledge of the complex family dynamics at play in this situation. Although the role of conscience was not explicitly stated in this story, it seems these relationships were also connected to the team members' consciences. Based on the description of conscience presented in Chapter Five, the team members' consciences likely influenced the team members' decision to continue returning to this family to ensure the patient received the care she needed, rather than abandoning the family after one conversation. The combination of all these factors led to the positive outcome described by the participant: this patient was cared for holistically by a care team that "took the time to listen to the patient," to understand her wishes at the end of her life and provide the care that achieved her goals.

It is also beneficial to describe the five themes that emerged in my research from the bottom up, from the least observable to the most observable. An engaged conscience is one that is actively involved in the world around it, prompting healthcare professionals to be aware of the values and beliefs of the people around them as well as their own values and beliefs. This provides the groundwork for the formation of real relationships that authentically connect team members with each other as well as with patients and families. In turn, these relationships ground holistic care, which is further bolstered by clear communication and a collaborative team approach.

As another example, I consider another story shared by a palliative care team member. This participant articulated the thoughts that went through her mind when caring for a patient who needed more help. She shared,

It was a difficult disease and it was a family member who was - I think - burning out even though we were trying to get more help in there. I think she was burning out and using phrases like, "we don't treat our animals this way," and, "we should be able to do something about all this." At the same time it was a client - her mother - in distress, and [I



was] trying to provide meds that she needed. But also [there were] words that she was saying that I thought, "I feel like I'm giving her the tools to actually end [her mother's] life. And it was very unnerving and I felt very uncomfortable leaving that home, and I actually at that point - I think I came back the next day and I was really distressed by it. So I think I actually put her on the waiting list for the palliative care unit fairly quickly with a bit of an understanding that this was kind of my gut feeling - you don't know. So that was helpful because she did get on to the unit and everyone got the cure they needed in that position. But I think there's an awareness - [...] it bothered me that I felt like I was giving her the tools [...] she could use overdosing. And we've been told that [...] if we were to give Dilaudid -for example - and give multiple doses of it, it still wouldn't end someone's life. But I was - there still was that feeling that was there. (I11 00:30:02)

This participant describes her own thoughts and distress over this patient to represent her conscience at work. Her initial discomfort was a signal that something was not as it ought to have been, and her moral reasoning engaged her conscience to determine what her actions ought to have been in this situation. In going through this moral reasoning, the participant described her insights into the relationship between the patient and her primary caregiver, her daughter. The storyteller's conscience seems to have been rooted in relationship with both the patient and daughter, as evidenced by her awareness of the difficulties the family was experiencing. This prompted the palliative care team member to consult with her team and to communicate to them her insights regarding the situation. This story again presents a positive outcome as "everyone got the cure they needed," a cure that holistically encompassed not only the patient, but her caregiver as well.

The analogy between the deliberative process of palliative care and the tree was not presented to palliative care team members for comment and is presented here to serve as a tool to communicate my interpretation of the findings presented in Chapters Four and Five. Figure 6.1 was created during the second phase of data collection after the session with the first interpretive panel. As such, it was only seen by the second interpretive panel and was highly useful in facilitating their discussion regarding the role of conscience in healthcare.

## **B. Interpretive Panel Findings**

Following their collection and analysis, the data from the palliative care team were presented to two interpretive panels of experts. The first panel brought together four members of management and leadership from the hospital in which the palliative care team was based. The second panel comprised four experts from the SHR's management and leadership, some of whom had academic positions in health science colleges as well. Both panels were asked to comment on whether the themes that arose from the palliative care team contributed to the successful mediation of conscience disagreements, and whether these themes might inform the development of policy and/or the practices of healthcare professionals in other areas of the Health Region. The questions and handouts that guided each panel are presented in Appendix B. The findings presented in this section parallel the five themes presented in Chapters Four and Five: clear communication, a collaborative team approach, holistic care, real relationships, and engaged consciences.

The members of both panels felt that clear communication was an indispensable tool for healthcare professionals regardless of their discipline (P2 00:38:57; P3 00:53:19; P5 00:07:48). After praising the positive steps many healthcare professions have taken towards improving communication with patients (P3 00:31:39), both panels focused their discussions on ways in which healthcare teams might improve their communication. For example, they cited charting more effectively and improving basic communication skills. When discussing the lack of charting on some units, panel members stressed that communication among some teams were often limited because multiple physicians will see a patient throughout their time in a hospital. Given that these physicians typically only record concrete decisions in their notes, "all the pieces

of the discussion leading up to the decision never [get charted]” (P2 0023:26). As one panel member explained,

It could be twelve different [physicians] that come through - so someone might be new to that patient - even though they're not new to the department, they're new to that patient. So when you talk about clear communication, the goals of care may not have been written down. They may have point [form] information, or a little bit of a transfer of information, but it's not thorough enough about maybe the values part. The clinical part might be really clear, but a patient's values and [.....] reasons that they made a decision - how they came upon their decision - may not be really well recorded. (P3 00:22:38)

This lack of attention to the patient’s deliberative processes was more prominent if the patient’s conversations with the healthcare team seemed ordinary or routine (P3 00:28:53). Although participants did not provide a reason for the scarcity of charting, one panel member explained that this issue was persistent whether or not the decisions being made were about end-of-life care. It was problematic because other staff members might “come in later [and realize] that [they] have no idea why [a] conversation was happening” (P3 00:26:03). To counter this problem, one participant suggested using a document for a “value based conversation” regarding goals of care, explaining that as a healthcare professional “when you meet with people you can go through [the document] and it gets people to think about what the values are of their loved one” (P3 00:32:59). This participant later elaborated,

I think we need to have a structured way to assess people's values and their understanding - some sort of record to know what they've understood or what they've been told because right now there's no way to know from person to person where that person is at. So you can have another team member come in if there was some way to now carry on the conversation. But we need to have some record of the conversations. There needs to be more to it than that. There needs to be some way of - there are decision making tools out there that get to one point and then unfold to the next part so at least you know what point in the process you're at so there's a record of that conversation. (P3 00:51:43)

Electronic charts were also considered as a possible solution, but the panel felt these might not get to the root of the problem (P2 00:53:01).

In addition to their discussions regarding charting, panel members also lamented the lack of communication skills among some physicians in the Health Region, proposing that medical students could develop “a set of skills [...] so they aren’t coming out of university lacking those skills in the first place” (P1 00:32:08). Another participant elaborated on this point, stating:

[As] health professionals what are some of our basic responsibilities [...]? Even now [when I'm] healthy and on no medications, I should still know what my end-of-life wishes are, because I don't know what's going to happen to me tomorrow. How do we help people start to think about that so they don't leave others in a bad place. It's not different from when they say we should be talking to everybody about smoking and doing smoking counseling when we have the opportunity. Is it just a basic skill or is it not? (P2 00:32:23)

Another participant stressed that academic colleges have made communication skills a priority, reflecting,

In the past the focus was on content and being able to understand the content - the knowledge and content. Now the focus is not just on knowledge, but also the means to deliver that knowledge effectively, and that's where healthcare providers struggle. I would absolutely agree that there needs to be greater focus in educational institutes on this. I know the College [of Medicine] has taken certain initiatives: [someone I know] comes as an examiner, [and] I've heard her talk about different methods they're using to examine students in terms of being able to empathetically deliver information in a way that is more meaningful and respectful to the patient. (P5 00:50:28)

Panel members also commented on the importance of developing both proper charting techniques and communication skills to improve conversations about end-of-life care, particularly once physician-assisted death becomes part of these conversations (P4 00:53:49). Regardless of the content of conversations among healthcare professionals or between healthcare professionals and those they serve, clear communication was accepted by the panel members as a necessary tool that enables healthcare professionals to provide holistic care that honours the patient’s goals of care (P7 00:33:21).

As witnessed in the panels’ discussions regarding communication among team members, panel members affirmed the value of a collaborative team approach both for palliative care (P2

00:15:29) and for other healthcare disciplines (P6 00:09:21). Participants shared that some teams were making positive steps towards adopting a collaborative team approach. For example, this was developing by holding daily multidisciplinary rounds (P7 00:38:56), particularly on smaller units such as paediatrics and obstetrics (P2 00:25:06). However, although the potential for a collaborative approach existed throughout the Health Region, participants stated that it was not always fostered. Drawing on her own experiences with palliative care, one participant explained:

Because there's a sense that you have to bring yourself, there's also other supports that [palliative care teams] build in to support you to be whole: debriefing, watching out - when I was there they had a secret buddy thing where you might be my secret buddy - and I'm just watching out for you. People would leave little notes saying, "after so-and-so's-death, you did a great job there." [...] There was that intentionality in the team to pay attention to where people were, and when I went into acute care to work - the pace [changed]. I kept thinking, "oh, that's the type of relationship that you would have in a busy oncology room." [...] Some of the elements [of palliative care] were there [in oncology], but then when I became a consultant I would go to medicine and they would have just as many deaths but the same attention to the personal piece and the resilience and the team [looking] out for each other wasn't there. (P6 00:09:21)

Panel members generally agreed that the shortcomings in team collaboration were largely due to the size of many healthcare teams as well as the type of persons that these teams attract.

Commenting on some of the challenges faced by large healthcare teams, panel members stated that these teams' low staff to patient ratio (P3 00:41:25) and high turnover rate have resulted in a situations where "some [team members] may not even know each other, or hardly know each other" (P2 00:40:06). This was seen as being particularly true on internal medicine units, and while some panel members felt healthcare professionals self-select to be on large teams to ensure more flexible scheduling (P2 00:40:43), others felt that internal medicine could adopt a team structure more similar to that of palliative care if these teams committed themselves to developing microsystems. As one panel member explained, microsystems might provide internal medicine patients with the benefits of being cared for by a collaborative team:

Some of the literature around how to make small change and how [to provide] care is switching to the concept of microsystems. So instead of trying to look at medicine as one, big, gigantic mammoth, [we should] break it down into smaller microsystem pieces. Because in a way palliative care is a contained microsystem, which allows you to make change. So how can we even start with that? Co-location would be one example of how to get a microsystem, to then actually be able to implement change. But I think it's still very much at the "how do we make this happen" [stage], in a very complex system under stress. (P7 00:17:47)

This participant further explained the benefits and challenges of co-location:

We're often spread over all six floors so then the team becomes nursing staff and probably five or six different - medicine, surgery, emergency - we're everywhere. Which is challenging because the sense of team becomes geographically and personally fragmented so that makes it more difficult to bring some of these pieces in. [...] That certainly has been a major drive - co-location - for an inter-professional health team to have the same people with the same group of patients as much as possible. That has been a major initiative of the Region. [It's] very challenging to [accomplish] because system factors tend to overwhelm that - we need to get people out of emergency, upstairs, anywhere where there's a bed, and that often tends to have competing interests. It creates a different kind of environment. (P7 00:16:27)

Participants acknowledged that forming microsystems might be a significant undertaking for a discipline such as internal medicine; however, it might improve patient care by ensuring that healthcare professionals have the support of a team and are accountable to one another (P6 00:18:28; P7 00:55:29). Although the palliative care team greatly benefited from being a smaller team that was primarily, although not exclusively, centered on one unit of the hospital (P4 00:37:31), their commitment to a collaborative team approach could be encouraged in other areas of the Health Region if more attention were given to forming microsystems within larger teams.

In addition to their discussions regarding team structure, panel members reiterated the palliative care team's feeling that this discipline draws a certain type of person (P4 00:37:31; P6 00:09:21; P7 00:14:08). Stressing the uniqueness of palliative care physicians, one participant explained,

The group of physicians on palliative care [are] a small number. If a physician doesn't fit they know really fast too and they don't stay there either. But when you get on bigger units

and people will rotate - physicians go unit to unit - they're not assigned even to a unit. So for them to get to know even the staff to form relationship [is difficult]. (P2 00:42:50)

Another panel member pointed to the hierarchical nature of many teams as another challenge to employing a collaborative team approach, sharing that, “some doctors are very good [at] listening to the nursing staff and [...] allied healthcare workers, and others still maintain that, ‘I’m the king, and you will’ [approach]” (P1 00:42:28). Added to these team dynamics, one participant also mentioned the challenges of incorporating physicians from different cultures who “bring their culture, the informed values of their medicine to the bedside as well” (P1 00:43:21). These cultures do not always “mesh well with how Westerners see things” (P1 00:43:21), which is challenging not only when bringing in different physicians, but also when caring for patients from difference cultural backgrounds (P2 00:43:40). Despite these challenges, panel members generally felt that academic colleges were making an effort to educate physicians to be twenty-first century physicians. As one team member explained, these efforts are exemplified in the Royal College of Physicians and Surgeons of Canada’s CanMEDS competencies that emphasize shared decision-making and patient-centred care as necessary components of patient care; however the “biggest challenge [...], especially for post-grad education, is [that] the curriculum, or what residents learn, is the learning environment” (P7 00:45:47). The learning environment for students, i.e., the current healthcare system, does not exemplify these competencies, which means that new physicians “have to break patterns, which is very difficult to do” (P8 00:46:58). One participant further clarified:

[The] curriculum is the learning environment; the learning environment is the curriculum. The learning environment is the practice environment, so really the practice environment drives how people learn, how we assess, and that kind of stuff. [The mindset right now is] we need to align continuing professional development with practice redesign [and] with residency education because they're all the exact same thing and the whole goal is patient outcomes. That's why the Region and the College [of Medicine], for example, need to much more heavily overlap what we do because we're both trying to achieve the same

thing, but now we're different entities. It's very clear that physicians need to have these skills; the goal is to have them have these skills; we're trying to figure out how to assess that because you don't just assess the knowledge - they can repeat back a checklist. You need to see them in action doing this. You need to have an environment that gives them the opportunity to do that and [gives] me the opportunity to observe them do that. We need to redefine what teaching is. The College needs to redefine what teaching is. Right now, it's me being in a class room. It's not being on the ward coaching or mentoring a resident through doing something and then sitting down and giving them feedback. That's not how teaching is defined, and if that's not how it's defined, then how are we ever going to make change. Education is in the exact same state of disarray that healthcare delivery is. Which is good! Because that messiness is where they are both going to learn from each other and we're going to improve. So what we should be - it's there - the educational approaches for how to get there are there - but now we need to have that space in the practice environment to make practice environment changes, which makes education a change agent for practice environments, which is good. And vice versa. (P7 00:47:01)

As well, these challenges were seen as being present in nursing because “in practice [nursing students are] seeing [people who think communication is] a soft skill” (P8 00:49:27). This need for a change in the culture of the learning environment was echoed in the panel members’ knowledge of the current Western literature on this subject (P7 00:48:46). Although it was a struggle, professional colleges were trying to form health professionals who are able to collaborate with their team members.

Panel members agreed that clear communication and a collaborative team approach were only valuable insofar as they were put at the service of a holistic approach to patient-centred care. Panel members reiterated the benefits of a holistic approach presented by the palliative care team, for example, ensuring the patient is discharged to a supportive home environment (P8 00:37:49), and stated that most units shared this approach to holistic care through initiatives that encourage interdisciplinary teams to involve patients and families in decision-making (P3 00:25:44). In their conversations regarding holistic care, panel members focused on palliative care’s ability to be process-oriented and set clear goals of care, as well as the challenges faced by other areas of the healthcare system.



The palliative care team benefited from several advantages, many of which aid them in their efforts to be more process-oriented in their approach to patient care. For example, several panel members pointed out that the palliative care team was often working with patients and families who have had time to adjust to their prognosis (P1 00:14:54), while other areas of the hospital, such as the ICU, often need to push families for decisions regarding patient care (P4 00:27:14). Although participants were aware that palliative care does not deal exclusively with patients who have adjusted to a terminal diagnosis (P2 00:17:56), one participant elaborated the differences between most palliative care patients and the patients seen elsewhere in the hospital:

I think if [a patient and family are] entering palliative care, they're seeing a certain trajectory over the time ahead, whereas in some other areas there may not be that latitude. So it may be necessary to have that conversation even if people are not ready, and that's the difficulty of doing ethics. It's like when we're in denial, and what do we do here? Because how are we going to get them out of denial and making a good decision or in denial and still making a good decision instead of making it out of that place that says, "this isn't real." So that's the challenge - I think that would be a challenge in ICU, oncology, down in the emergency unit. (P1 00:34:20)

Much of this discussion focused on the palliative care team's ability to clearly express their goals of care and to work with patients who shared those goals. One participant explained this advantage, saying,

I think the structure of your work - the way you work - influences [your ability to clearly state the goals of care]. When I think of palliative care, in many cases in acute care they're consults. They might work with the family, but they may not be the primary - they may not be getting the exact same messages as you are because they're being asked to come in and provide this piece, but they may not be getting the same pressure that [acute care] is getting. I think the palliative care unit might look different as well versus home. Your environments [probably] also influence how much control you have to buffer some of those pieces too. (P6 00:42:47)

Another participant also emphasized that acute care teams often work under unrealistic expectations from families who look for a cure; however, "the healthcare reality is, 'we don't get people better anymore'" and care teams must work towards realistic goals that do not always

include a cure (P7 00:56:16). Panel members explained that in an effort to ensure team members and patients agreed on goals of care, the Health Region had made several changes in their policies regarding end-of-life decision-making. One participant explained:

We have changed our process a fair bit in the past five years - so we do get goals of care within the first day - we usually get goals of care within the first hour. We do meet with families right away; we do start conversations: "I think you might be afraid they might die, and we're afraid for that as well." We start those conversations really early now. Some people want to hear that and some people don't. So then we kind of feel our way through. (P3 00:28)

Participants shared that the Health Region had crafted new policies, such as their policy on resuscitation, that required staff to have a conversation regarding the goals of care within 24 hours, although the uptake on these policies had not yet become universal (P1 00:29:06). The Health Region had also launched a new initiative for "Patient-Resident Empowerment" to spotlight the Region's commitment to patient-centred care that could potentially improve holistic care across the Health Region. Participants also referred to certain American states that have mandated conversations about issues such as organ donation as a possible exemplar of how policies could facilitate conversations about the goals of end-of-life care (P4 00:29:42).

Panel members agreed that holistic care was desirable across the Health Region. However, they also acknowledged that most care teams were faced with challenges that made this goal difficult to achieve, such as a physical environment that does not support patient-centred care, the different work cultures present on other units, and institutional constraints. The physical space on the palliative care unit was perhaps one of the most obvious advantages of the palliative care team (P6 00:12:53). As one panel member pointed out:

If you have a shared room with four patients and families and that's the space where you're trying to build real relationship and trust, you're always aware that there's three other people in the room listening to every conversation. With patients and families - there's no meeting space really to go to. And even in terms of staff, there's no staff space. There's no place the staff can really go to debrief. There's a nursing break room, there's a residents

teaching room and there's one common room - but the common room shares four units. So [one of the] things that might facilitate bringing the cultural practice into the environment is physical space, which is also very challenging because there's so many demands for space and multi-use for space. I think not just co-location but the actual physical environment has an impact on facilitating some of the team pieces that you want to build. (P7 00:19:51)

This participant provided a helpful example of the impact these limitations might have on a healthcare team's ability to work collaboratively as well:

For example, we have our multidisciplinary round every day, it's: physio, OT, pharmacy, social work, homecare, physicians. We actually are in the hallway because we're moving unit to unit to also involve the nurses. It's interesting because we've done some qualitative research around the bullet rounds, and in terms of the team relationship part, the actual bullet rounds is a very - even though they're fifteen minutes a day - they are huge in building the team. And you're in a hallway - in a public space, in a hallway - that's the only space we have to do them in order to engage the nurses. That's our space, with the floor sweeper driving around us and the pharmacy carts driving around us, and stretchers driving around us, and us trying to be as confidential as possible because we can't use names in the hallways. It's challenging. (P7 00:38:56)

Panel members understood that, environmental concerns aside, some units were simply challenged by their own cultures of care. Reflecting on the expectations of patients and healthcare professionals in acute care, one participant pointed out that shifting to a holistic approach to care was difficult “because you need a cultural shift, which is always really hard to do” (P7 00:14:08). This participant further explained,

There's been intermittent innovations - there's Lean 3P model of care, there's nursing coaching going on to try to bring it - policy is always a challenge to figure out how to direct policy that's going to drive culture change. I think the interest and the want is there, but [the business side of healthcare] just overwhelms the intention of VPs. (P7 00:14:08)

For example, participants felt that conversations about end-of-life care were more difficult to initiate when families did not have time to adjust to a terminal condition (P4 00:27:14), or, at the opposite end of the spectrum, when a patient was not gravely ill. As one participant explained,

It's hard. If you talk to surgeons - they're bringing somebody in to operate on their knee. The risk is very low, so for them, they have a hard time - if you talk to surgeons, some of the surgeons anyway - about talking to someone about their end-of-life wishes. They [say], "they're coming for a knee and you want me to talk to them about that I might kill them?" (P2 00:30:16)

These sentiments were echoed by another panel member who stated,

[The avoidance of conversations regarding end-of-life care is more prevalent] in certain professional groups more than some others - surgery being one of them, hematology and oncology being another - where there's a reluctance to have conversations about realities. So you come in and you're diagnosed with cancer, if you don't proceed with chemotherapy, then you're going to die. That should be raised and the possibility of palliative care should be raised at the time of diagnosis as far as I'm concerned. So, yes, legislate it. (P1 00:31:06)

Some participants proposed that physicians whose patients were relatively healthy might rely on other team members who were skilled in facilitating end-of-life conversations (P3 00:46:53); however, one participant felt that it was more important to realize that holistic care was not identical throughout the health region, explaining,

The holistic care program at palliative care and the holistic care program in medicine - they're not comparable. They have different resource constraints, and they have different concerns that need to be addressed. So yes, while palliative care is very good and very successful in the holistic care of their patients, that doesn't necessarily mean that others are not. Each program has to work within the finite resources that they have, and the constraints that they have, which are very unique for the services that are being provided. So quite often ethics gets called with regards to patient discharge and one of the [most common] arguments that we hear is: "this needs to be holistic care." There are constraints to a holistic approach in a system that is unreasonably burdened with severe constraints in resources, and when you have competing priorities, you have to make tough decisions. It's not that they don't want to; it's that they're unable to because they do not necessarily have the means to provide that care. (P5 00:43:33)

In a different vein, another panel member mentioned the challenges of providing care in a healthcare system that must adhere to the regulations of multiple institutions, such as professional regulatory bodies and unions, observing that "all these accountability structures bump up against that ability to be - as a team – holistic" (P7 00:33:21). This participant elaborated:

I even think about patients where harm has happened. We're working side-by-side, walking through with them, helping to understand what went wrong - we do this and then all of a sudden there's this litigious legal system: "stop talking." We talk about team [...] - we're all part of the team - and then all of a sudden as something goes wrong, it's, "which insurance is going to pay for what piece?" Then all of a sudden it impacts, "are we a team?" There's these other competing things in an organization that I think ripple down. It may not seem like it; we may not think about it, but it does influence some of the day to day messaging and the work [.....]. (P7 00:33:21)

Another participant more fully articulated these concerns, adding,

There are competing priorities - maybe to legal and organizational policies governing the process. But [but providing holistic care with limited resources] has an inherent ethical dilemma, dealing with competing obligations. As an employee of the Health Region, you are expected to act as stewards of the resources, but as a care provider you expected - not just ethically but also legally - to act in the best interest of your patient. [...] The concepts of best interest and stewardship conflict at times. When we're talking about flow and providing access not just to one person but to other persons - where you are acting as gatekeepers and stewards - that's where best interests collide. So it might be, professionally, in the best interests of your patient to stay a few more days even though they don't need it, or may not necessarily benefit from it, or might just psychological benefit from staying a few more days in that particular facility. [However] it may not be good stewardship of resources when you know there are people waiting in the ER who desperately need those resources. You can have an inherent conflict here. (P5 00:35:47)

While many of these problems might be resolved in a system with infinite resources, participants expressed frustration at knowing what best practices look like but being unable to achieve these goals due to lack of resources.

The challenges of balancing the provision of holistic care with the healthcare system's need for discharge planning was discussed at length by the second interpretive panel. Several participants felt that the system's emphasis on discharges was damaging because conversations about discharge planning often eclipsed conversations about patient care (P7 00:38:56).

Participants felt that this occurred because at meetings team members were generally asked about discharged planning before anything else, which sets the tone for the entire conversation.

As one participant explained, "the first questions you ask tell you what's most important" (P6 00:42:00). This participant elaborated, sharing,

One of the things I always notices at the bed side [...] is that what I got asked every day about my patients told me what was important - and what I got asked about myself. [I] worked for different leaders who every day would say, "what's most important for the patient and family today?" or, "what [are] Mrs. Jones' goals?" And if you didn't know, you knew tomorrow you better know that because you were going to get asked a similar question. That question. Or even - I used to work with a physician and if I was in charge and when we did rounds, he would challenge me as much as the residents. I had to answer the questions just like the residents had to answer, so I would be studying the night before to understand [the technical aspects of care] just because I knew that would happen. So who you work with and what the questions are - it's kind of like what [P7] was saying - if every morning the question to me is, "can they go home today? Are we done this today?" If it's all about [...] the system or transactional pieces, then that's what's being messaged to me as most important and most valued. I think we've got to find a balance. It's not that getting patients home isn't the most important thing - for some families they actually want to do that - but if that is the only thing [we focus on] in light of what's important and the goals they have or even understanding what those goals are, it's challenging. (P6 00:27:54)

In addition to its impact on patient care, another participant stressed that an overemphasis on discharge planning also had repercussions on healthcare professionals' abilities to function as a collaborative team:

We've done focus groups and interviews around bullet rounds as well as some ethnography, and healthcare practitioners will tell us they stop participating in the conversation because the purpose of the rounds of care coordination get hijacked and so they don't think they have anything to contribute, so it actually disrupts the team. So there's many factors [that influence team building], which I think palliative care has done well to create an environment where those kinds of activities are encouraged. A lot of acute care has so many conflicting messages that it doesn't necessarily promote the activities that need to happen, even though the activities are actually occurring. (P7 00:42:12)

While some panel members focused on encouraging individual healthcare professionals to strike a balance between conversations about patient care and conversations about discharge planning, others focused on the resources in ethics that were already in place to help team members, patients and families strike this balance (P5 00:29:35). Regarding the role of policy in promoting holistic care, the second panel's sentiments seemed to be summarized by one participant, who stated,

I do think that we tend to try to design and put things at [a high level]. I think we've got to go back to that micro-level design and really what are the supports around a micro-system

that enables [accountable teams] to work through how to [meet challenges]. To me I think at a high level we've got to really question if the work needs to happen and what are the supports? Are they in the right place? (P6 01:00:27)

Holistic care was valued across the Health Region; however cultural and institutional constraints limit the care healthcare professionals were able to provide.

Members of both panels agreed with the palliative care team's assertion that holistic care might be either reinforced or undermined by the quality of relationships shared among the healthcare team, patients and families. One participant highlighted the role of relationships in the provision of care, sharing,

Every time [the hospital gets] a letter that [says] what good care someone got, it's because people were there, they listened, they gave people the time and they developed a relationship. And every [the hospital gets] one where it's not so good, it's: "people didn't listen; people didn't ask; I wanted this and I got that." 90% of the time at least, it's communication, it's not other stuff. (P2 00:38:57)

While panel members stressed the importance of relationships in healthcare, they were also aware that many healthcare professionals who come from a more paternalistic background do not share their understanding of relationships, which posed considerable challenges in the provision of patient-centred care. As one participant explained:

It's almost the system - ["them"] - trusting the patient. And of course, especially medicine likes the evidence-based medicine piece. There is increasing evidence in the literature that if you sit down and talk to patients about goals of care, tend to do less tests, less procedures - it costs less and there's less time in hospital. But when I bring that up with people, they say, "but we can't let the patients make the decisions; they're going to ask for everything; they're going to want everything." Again, because it boils down so much to money, it's, "we the system must hang onto the purse strings. We must be accountable." Even some of the e-mailing message from the Region right now about the deficit is: "please think twice about ordering tests." Maybe the message should have been: "please sit down and have good quality conversations with your patients and families about what their goals of care are." But instead the onus is put back on the healthcare provider to be the gatekeeper, and control tests and procedures, and everything else. It's interesting: even the message from the Region to us as healthcare providers is: "we are responsible for what the ultimate decision is around who gets a test or not." For the Health Region to let go and encourage providers - professionals - to allow patients and families to have that decision - it just isn't

there yet, even though the evidence is increasing that we should be moving in that direction. (P7 00:31:30)

Although individuals with a variety of beliefs serve the healthcare system, panel members observed that palliative care attracted people who value relationships (P6 00:09:21). As one team member highlighted, this was true not only of healthcare professionals, but of patients as well:

With the real relationships part, there's a literature in palliative care that talks about how people [develop] relationally and spiritually as they're on this trajectory towards death, so maybe that's contributing to where the patient is in their journey and their acceptance. Because once you're in palliative care, if you're a person with capacity, then you've accepted that in fact you're dying at that point. That could be a contributing factor from the patient's side. (P1 00:14:54)

In concert with the palliative care team, the interpretive panels also highlighted the role of trust, honesty, and the relationships among team members as key factors in forming relationships. They also addressed the challenges faced by teams outside of palliative care services and explored some possible avenues for the future.

Panel members recognized trust as the foundation of healthy relationships between healthcare professionals, patients, and families. One participant shared,

What I have certainly seen in [my work] is that once there has been a violation of trust between a provider and a patient, there is a domino effect after that. One of the first things to break down is the communication, and then there's a domino effect where engagement, collaborative approach and holistic care and relationship building - they all break down after that. I think trust is perhaps the most critical aspect of relationship building that plays a role not just in palliative care but [in] interdisciplinary relationships as well. (P5 00:23:11)

Another participant elaborated on this comment, by exploring the role trust played in building authentic relationships

If there's an experience that's not good - and that may relate to a complaint or something else [...] - I'm thinking about healthcare providers [who] lose trust with patients and families, and patients and families [who] lose trust with the healthcare providers - then it's really difficult to make those real relationships actually occur. It sounds like in palliative care [...] there's ways [to work through that] if it does happen. I think one of the things that you tend to find on acute care is that those pieces aren't really in place. Some of that



comes through - I mean the knowledge base is probably human factors, engineering [teams] - in team collaboration they talk about conflict resolution that needs to extend in multiple different ways - but that's the one piece I've never seen. And I can see people being healthcare providers, but also friends of mine who have been in and out of the hospital frequently, there's that lack of trust between the provider and the patients. I think that trust exists and is built between patient and healthcare provider on palliative care and there's ways - again it's culture but also processes to help that happen. So it's the real relationships piece and the aspects around that [...] that could be transferred into acute care as something that's really key. Because lots of times we do manage - even though we see people infrequently - we do manage to start to build those team relationships. (P7 00:24:15)

Panel members recognized that trust building was influenced not only by the skills and empathy of the healthcare professionals (P5 00:26:25), but also by the resources the health region is able to invest in developing relationships. The primary resource discussed by the interpretive panels was time, as several members felt that palliative care interacted with patients for longer on average than most other units, enabling them to develop a strong foundation for their relationships (P1 00:35:38; P2 00:24:15). The experience of building trust was substantially different for healthcare professionals who only saw patients “at one point” in their history, making it “hard to be on the same page as they are to come to the decision” (P3 00:24:28). Although time might be extremely beneficial to healthcare professionals, panel members also recognized that there are ways to develop a relationship in a brief period of time. One participant explained,

I think you can develop a relationship in ten minutes. When we've had people come in that are so bad off that you start to talk to them and you just let them talk about what's going on, and you say those things like, "I know you're afraid she might die and so are we," and you have those conversations. "How about you come in with me and we be with her right now. And you just talk to her as much as you want." You do those kinds of things and if you just spend time with that person, they'll talk to you. But you have to spend the time with that person. You have to give them somebody to be with them. You can't just assume that's going to happen if you let them go sit in the hallway by themselves or at the foot of the bed. You need to have someone spend the time with them. So it just takes actually having somebody talk to them; [for them to] know that they're there to talk to them, not to be just hauled off to do something else. (P3 00:36:20)

This participant also explored other ways that healthcare teams, particularly larger teams, might build relationships with patients, sharing that often quality was more important than quantity when spending time with patients:

So you really need good communication. Even for relationships - we've had circumstances where it's been a longer term patient, so we would try to narrow it down to a couple of people who would be the caregiver or the physician so when those things come up - because we know it's going to be for months - then they are responsible for those ultimate bigger conversations. We do try that. And it is helpful - then you get more similar to the palliative care model. But it doesn't always happen, and it happens sometimes sooner in some circumstances than you realize. (P3 00:23:39)

This patient-and-family-centred approach to care also affected this panel member's reflections on honesty, as she stated,

I think it would be interesting to find out - when you talk about being able to speak to someone about [the fact that] you disagree - how much of that you're suppose to have with the patient. You can very much disagree with the patient, but do they need to know how much you disagree? When they're in that point of their life, do they need to hear how much you disagree? Do they need to defend their opinion or what they want to do? I have a hard time with that. We talk to staff about, "patients don't have to justify their decision to you." Sometimes people decide that today is the day that they want to [discontinue their treatment]. And a team member may come on that week and have known that person, and they're not ready for that person to say, "this is the day," but the other team says, "no, no, they've been going through this for quite some time." And [the first team member] has been able to step back and say, "okay, if we know that we've done all this, then we know we can do other things." But it's hard for people when they come in and the staff aren't at the same page as the patient and their family because they haven't been journeying with them the whole time. They don't say, "no, because I'm not ready," but they might want to. So we have a good team that will step back and [say], "if you believe the doctor last week was fine with it - had that whole conversation, the whole communication - then I will step back." (P3 00:19:59)

Building authentic relationships presented a great challenge to healthcare professionals, who, as panel members observed, must carefully earn the trust of their patients and their families.

Trust was seen as an integral component of forming relationships among team members and, in turn, bolstering the other tools used by healthcare teams. As one panel member explained,

Communication, collaboration, real relationships – [they] take trust. If you actually don't spend time together, it's very hard to create trust. I was on ortho the other day, and we were

in a huddle, and there were thirty-five nurses and sixty physicians, and you say, "how can you feel [like] a team?" There's never a day where you and I [would work together]. [We] might work for six months and only have one day where she's the physician and I'm the nurse that actually happens to be with the same patient. [...] if you want to create that trust and that holistic look at the patient - [it's] pretty hard. We're all individuals so you have to learn each other; you have to build that understanding of each other. (P6 00:18:28)

In addition to improving the team members' inter-professional skills and providing space for constructive criticism (P6 00:22:09; P8 00:20:50), panel members felt these relationships might also improve care by ensuring care was provided by team members who were best suited to certain tasks (P6 00:22:27). However, despite these benefits, relationships among team members remained difficult to develop due to previously mentioned constraints, such as large teams and low staff to patient ratios (P3 00:41:25). As discussed above, these stressors might be relieved with an emphasis on microsystems and co-location.

In addition to these challenges, panel members explained that the culture on many units, outside the palliative care unit, was not conducive to forming authentic relationships. As one participant explained,

I think part of that too is [is that the value of relationships has] been recognized and valued [on palliative care]. That's not so much been recognized and valued [in acute care]. What's important in acute care is "get people home." Get people out so we can get someone else in. I think that relates back to policy and organization and structures. How do you bring that forward as a value? Because that unfortunately is not a value on acute care. (P7 00:27:36)

Participants also drew attention to the Health Regions' focus on forming professional boundaries, which might dissuade healthcare professionals from forming appropriate relationships with their patients (P8 00:35:14). However, participants felt that this culture was already changing as the organization began to value "co-production," which encourages "equally shared participation" between healthcare professionals, patients and families (P7 01:04:04). As one participant explained,

Where I see [things] going really well is there's a mentality shift that really says, "the most important work is that between the clinicians - or the support - and the patients and families." It's almost shifting the organization. The role of the manager is not to take what's coming [from higher up down]; the role of the manager is to support and be present and to be breaking down barriers so that these people can do what the patients and families they know need. You have to justify your value at the next level by what you provide to those people to do the work. It's a completely different [perspective] - when I think about being a manager, [I think], "what is my director telling me I need to do?" It's almost I'm saying, "in order to provide this they need" - it's not always more, but it needs to be a shift in how we think about things. (P6 01:02:54)

Looking to the future, participants felt that the next step was to ask: "are we willing to be present to the patients and families - to have those real relationships" (P7 00:24:15)?

In their discussions regarding relationships, panel members also focused on the need for healthcare professionals to bring their whole selves, including their consciences, to their work. The palliative care team's description of the three facets of conscience; namely, conscience as that which tells us right from wrong; conscience as that which demands conscientious work, and conscience as a navigation tool, resonated with members of both panels (P1 00:13:41; P5 00:07:48). In particular, panel members focused on the navigation role that conscience might play in aiding healthcare professionals when they interact with patients and families. As one participant explained, healthcare professionals must be careful "about even asking questions because the uneducated family will take that as an instruction, not a question" (P4 00:47:38.2). Participants discussed the danger of being coercive with patients and families, suggesting that self-awareness, particularly of their beliefs and values, was needed for healthcare professionals to be able to navigate the line between informing patients and unduly influencing their patients (P1 00:13:41; P2 00:46:07). One participant explained the value of self-awareness, noting as well that some people, including healthcare professionals, struggled to be self-aware:

I would suggest that [engaged consciences] always requires a degree of self-awareness. Irrespective of nurturing and education that you provide, if individuals lack in their ability to reflect because they do not have the necessary self-awareness, those are the inherent

challenges that come about. It's not just the healthcare system it's the culture - there are cultural practices that discourage, for example, empathy, or discourage emotional attachment of any sort. In certain cultures, people may be less self-aware than in other culture, and even within a culture there are degrees of self-awareness based on gender - there are certain expectations of a man, and there are certain expectations regarding a woman's behaviour and approach where culturally it is acceptable for them to be empathetic, nurturing, caring - whereas for men it's not acceptable for them to be that way. Those are the inherent challenges beyond the organization that have to be addressed as well. (P5 00:57:54)

Another participant reflected on the important role that self-awareness played in patient care, sharing,

It's an interesting thing because - engaged consciences - [...] maybe how I'm thinking of it is: my own self-awareness. My ability to see myself as well and understand myself in order to engage with others. [...] In other positions I've been in, - I've taught courses in patient-family-centred care that are very experiential - I remember nurses coming in and [saying], "I'm not doing this. This is insulting and I'm not doing any of this piece." And through the process, [they would have these epiphanies about where] they'd lost their connection about why they'd come in to care. [...] You'd have reflective time, you'd be reading, you'd be talking about patients - kind of as you would do with students - and then you'd go back into practice, you'd have a few hours, you'd be back practicing, and they'd come back next week with stuff. That learning piece really re-sparked for people why they [entered their profession] and they started to be aware of how they'd been on this wheel of coming in every day and doing "my tasks" [...].(P6 00:52:03)

Continuing to reflect on the program that was offered to nurses, this participant further elaborated on the integrity of conscientious individuals:

When [students in the experiential patient-family-centred care course] were asked to go back and connect in a different [way, they saw] how their environment over time had actually [made] them lose why they came into this. I think they came in with consciences - and it's not that it's totally gone - it's just that they start to put barriers around themselves, or ways to get through the day, [...]. (P6 00:52:03)

In tandem with the palliative care team, panel members also linked engaged consciences with the ability to care for patients and families. As one participant stated,

I don't think it's possible to work and not show that you care. If you don't care, then the person would know that you don't care. I don't think you could fake that. If you treat them like they're just a piece of equipment - I think it could be a problem if you were trying to impose your will. I think you have to have some will - you have to have some consciousness. (P3 00:44:56)

Another participant commented that while you cannot “turn your conscience off [...] you can train yourself to try not to impose your conscience on someone else and spend more time trying to make sure they're making informed decisions - that they have all the information they need to make the decision” (P2 00:44:26). Participants stressed that this was a challenge for healthcare professionals, particularly in situations of “true ethical dilemma,” where a healthcare professional does not want to carry out a patient or family’s decisions because he or she believes they would harm the patient (P1 00:46:29). The engagement of an integral conscience was also identified as a necessary component of authentic relationships that help healthcare professionals to “understand what the patient is facing and what their concerns are” (P6 00:07:48), as one participant explained,

With conscience, empathy goes hand-in-hand with the practice of palliative care. [...] When staff engage with patients and they're asking about how they're doing - how they're feeling - they're experiencing. They're going above and beyond ensuring them - they're connecting at an empathetic level. (P5 00:12:27)

As a corollary to the positive impact empathy might have on relationships, emotional disengagement, putting up boundaries and withdrawal had a negative impact on healthcare professionals ability to engage in their work environment (P7 00:55:05).

In their discussions regarding conscience, panel members also focused on the relationship between engaged consciences and moral distress. As one participant emphasized,

I think people are tired, and if you look at retention as a measure of job satisfaction, which probably relates very closely to engaged consciences, medicine lately has had trouble with nursing retention. Why? I don't think anybody really knows, but there's no way you're getting engaged consciences when you have massive turnover of staff, which is a reflection that something is not right in the environment. We can pull apart what those pieces are. (P7 00:56:16)

Repeated exposure to moral distress, particularly when coupled with messaging around financial rather than care concerns, might create a stressful environment for healthcare professionals (P7

00:57:28), which might impact their ability to stay engaged as well as their attendance at work, as one participant explained,

Being able to go home at the end of the day and you feel like, "oh I really made a difference to that patient" - that's what keeps you engaged and [gives you] satisfaction in your job, and [...] the next morning when you're tired - those morning questions and you're fatigued and it's 6 and you think, "I really would rather just phone in sick." There's things in people's split second decision-making that influence [them]: it's my team, how resilient I feel. (P6 00:56:56)

Another panel member stressed the need to not only respect but also to nourish the consciences of healthcare professionals, sharing,

I was just talking to the emerg staff about compassion fatigue. If you don't have time to debrief after you have a major traumatic event in your department, or you don't have processes in place, it's hard to keep that [conscience engaged]. Because when you're having that type of relationship with a patient, you're making yourself vulnerable in that too and if you don't have a safe way to keep doing that [it can lead to compassion fatigue]. I think the conscience is so important, and so much of our environment - it goes back to the teaching piece - we can teach our students but if we don't keep - when I think even of the Region [and] how much money we put into continuing education and reflection times. Some units have one education day a year. How do you keep a reflective practice, a self-reflection piece? Some people just naturally do that [because] that's part of who they are, but you have to water these roots [*referring to the roots labeled "conscience" on Figure 6.1*] or understand what's going on in the environment that impacts the roots. I'm not sure - in the practice environment - we pay enough attention to [the roots]. (P6 00:52:03)

The challenges faced by staff were articulated by another panel member, who commented on situations in which healthcare professionals were not comfortable with a patients' and families' decision to discontinue treatment:

I also have seen [in my area of healthcare, situations] where someone's had a very hard time dealing with someone's choice to go on or to not go on. And so sometimes that staff member removes themselves from the care team. Sometimes they're not able to remove themselves from the care team and they struggle with that. Sometimes the patient or the family members might sense that; other times they do a really good job of hiding it, so that when they leave they may not feel - sometimes they leave saying they don't feel that their conscience was right. We've had conversation about, "remember: that was about how you were feeling about it. How can we help you cope with that?" But you allow the patient to make that choice. (P3 00:16:48)

Understanding that these situations might lead to moral distress, panel members reiterated the importance of the coping mechanisms identified by the palliative care team members, focusing in particular on the support provided by a collaborative team (P6 00:09:21).

Both interpretive panels concluded their sessions by reflecting on the future of policy formation regarding conscience issues in healthcare. One participant tied the palliative care themes to policies that required healthcare professional to provide patients with information regarding treatment options that the healthcare professional may find morally objectionable, such as physician-assisted death, stressing the need to form policies that reinforce clear communication, collaborative team work, and holistic care, thereby facilitating the work of conscience (P1 00:50:33). Meanwhile the second panel was particularly vocal about the need for fewer top-down interventions by senior management and more empowerment of healthcare professionals at the bedside (P7 01:01:59). As one participant explained, policies that support rather than constrict healthcare professionals will be more likely to enhance patient care:

Within [the call for a less top-down approach] is that engagement pieces because by the time you're controlling from the top, patients get completely lost. If it's the people on the ground who are looking the patients in the eye, so to speak, and you're trying to encourage that relationship at that level, that's the empowerment piece, I think, of the healthcare providers and the patients both. [...] And what are their goals and healthcare provider goals, which might bring that engaged consciences back. (P7 01:02:27)

This participant also reflected on the challenges of changing the healthcare culture to foster rather hinder engaged consciences, sharing,

I mean the word "transformative" - which gets used too much - but that whole concept of how do you change an environment or culture which is transformative. The leadership part around that seems to be: it's relational, it's network, it's something needs to be small that fits into clinical micro-systems. So then how do you - as an organizational structure - develop policy that allows that to happen - at the big picture piece that, they actually [need to] let go of some pieces and allow ownership to happen at that smaller level. Maybe that's part of palliative care's success is that they have ownership of something that's - not defined - but it's end-of-life care - it's something that's defined. How can policy support that type of on the ground engagement and leadership? (P7 01:01:10)



This final question opens the door for more research into conscience issues in healthcare, as policy-makers need to address ways in which they might encourage clear communication, collaborative teams, holistic care, the development of real relationships, and the engagement of consciences as a means to improve patient care throughout the healthcare system.

### **Summary**

In this chapter, I completed my presentation of the findings gathered in this study. In the first section, I provided an analysis of the connections between the five themes that emerged during the first phase of data collection. Second, I presented the findings gathered in the second phase of data collection of this study. In this phase, the analysis of the interviews and focus group I conducted with the palliative care team in phase one was presented to two interpretive panels. In the interpretive panel sessions, panelists provided insights into the five themes that emerged from the phase one analysis and commented on whether the deliberative processes of the palliative care team could inform policy and practices in other areas of the healthcare system. The transcripts from the interpretive panel sessions were analyzed, and from this analysis five groupings of insights emerged that paralleled the five themes that emerged from the analysis of the palliative care team findings.

To the best of their knowledge, the members of both interpretive panels felt the five themes presented an accurate description of the deliberative processes of the palliative care team. As shown, panel members seemed to agree that these themes were present to some degree throughout the Health Region, albeit with variation due to the different ways that holistic care was provided by different disciplines. Further, the panel members listed several ways that these themes might be reinforced throughout the healthcare system, such as through a commitment to co-located microteams and through collaboration between the Health Region and health sciences

colleges to ensure healthcare professionals receive appropriate training in the tools needed to provide holistic care. In particular, conscience emerged as a faculty that, when working in tandem with the other themes, improved the care provided by self-aware healthcare professionals. However, there was some disagreement about whether self-awareness is a characteristic that all healthcare professionals are capable of developing. In their expert opinion, members of both interpretive panels felt that the themes articulated through my research could inform the creation of policies that support positive resolutions at times of conscientious disagreement. They also agreed that these themes could inform reflections on the deliberative practices of healthcare teams beyond palliative care, helping these teams to maintain the healthcare professional-patient relationship in situations that engage their consciences. In the following chapter, I will use the findings presented in Chapters Four, Five and Six to answer the research questions in the context of the literature reviewed in Chapter Two.

## **Chapter Seven:**

### **Conclusion**

#### **Introduction**

The previous six chapters detail the purpose, related literature, methodology and methods, and the findings of this dissertation research. In this chapter, I provide a summary of the preceding chapters, and use the findings from Chapters Four, Five and Six to respond to the following four research questions:

- (1) What are the experiences of team members who have been directly involved in decisions that engage their consciences within the culture of palliative care?
- (2) How do palliative care providers describe the deliberative processes used at personal, professional and team levels, regarding end-of-life care?
- (3) What part of the deliberative processes described by palliative care team members contributes to the successful mediation of conscientious disagreements between healthcare professionals and patients, as perceived by the healthcare professionals?
- (4) What aspects of palliative care providers' deliberative processes provide insights that inform the development of policy and/or reflections on the practices of professionals in other areas of the healthcare system?

Responses to these questions are followed by a discussion of the findings in the context of the related literature in this field. Finally, I provide an overview of the implications of my research for healthcare institutions, healthcare professionals, and users of the healthcare system, as well as its implications for the development of theory and future research.

## **A. Summary of Research**

In this section, I summarize the research contained in this dissertation. Before doing so, I restate the purpose, related literature, and methodology used for my research; then I use the research findings to respond to each of the four research questions.

### **Purpose of this Dissertation**

Our healthcare system is shared by all Canadians, and as such, value discussions and disagreements engage the consciences of many and diverse persons. Experience suggests that conscientious disagreements either have the potential to escalate into unhelpful conflicts, or to result in the positive resolution of issues for patients, families and healthcare professionals. Although researchers, media outlets and the public commonly give attention to situations that escalate into conflicts, I deemed it prudent to investigate a type of healthcare team who appear capable of positively resolving conscientious disagreements.

Although palliative care teams are frequently confronted by ethically challenging situations at the end of life, from which conscientious disagreements are likely to arise, they seem able to maintain positive relationships with those they serve. As such, palliative care teams provide an example of positive deviance that may be studied to determine which of their deliberative processes contribute to the positive resolution of conscientious disagreements. To reiterate, the purpose of my research was to articulate the deliberative processes that led to positive outcomes in situations wherein the consciences of palliative care team members were engaged and to explore whether or not these processes might inform the creation of policy or practices in other areas of the healthcare system.

My research informs the creation of policy on conscience issues, a branch of policy that shapes the ethical culture of the healthcare system. As outlined by Goodpaster (2007),

organizations that value the consciences of their members are able to develop and maintain a *culture of ethical awareness*. In the context of healthcare, such cultures have the potential to relieve moral distress for healthcare professionals, minimize instances of litigation between healthcare institutions and users of the healthcare system, and improve the relationships between healthcare professionals and those they serve. These benefits become increasingly significant as the Canadian culture, values, and ethics around end-of-life care adjust to the legalization of physician-assisted death.

### **Literature Review**

The literature reviewed in Chapter Two explored several themes regarding conscience. First, I defined conscience as a judgment about the morality of an act, which must be exercised externally to preserve the integrity of the moral agent, and highlighted its implications for both the individual and society. Second, I explored Vischer's (2010) concept of the *relational dimension* of conscience in tandem with other theories of relational ethics. Third, I provided an overview of the literature pertaining to conscience in the context of healthcare. Although I will not provide a detailed summary of the literature review here, I will highlight a few key points arising from the literature.

The literature review revealed a common understanding among conscience scholars that conscience is valuable to both the individual and society. This near consensus stems from an understanding that human freedom, first and foremost, must entail the freedom to follow one's deepest sense of morality and to construct one's own life narrative (i.e., to maintain one's personal integrity). Building on the universal right to freedom of conscience, some authors have focused on conscience as something that promotes the flourishing of communities (Stout 2010; Nussbaum 2011; Sen 1999), while others have attended to the role of conscience in institutions.

For example, Goodpaster (2007) introduced the concept of a “corporate conscience” that is fostered through a “culture of ethical awareness.” This culture ensures that the values of individual members of a corporation are respected, providing these members with the faculties they need to maintain the ethical behaviour of the institution as a whole. Given the importance of conscience for both the individual and the institutions in which she participates, preserving the moral integrity of individuals is beneficial for both the moral agent and society.

Second, the literature review also revealed a consensus regarding the role of conscience in relationships. Vischer presented what he called the *relational dimension of conscience*. He did so in order to explain that conscience must be exercised in relationship with others. This external orientation is beneficial not only for the conscience of a particular individual, but also for all those with whom this individual interacts. Vischer’s concept of the relational dimension of conscience is compatible with feminist relational theories of ethics and law, which also emphasizes that individuals are enmeshed in relationships. These relationships can be positive instances of influence or negative instances of power, and have a direct impact on the development and exercise of conscience.

Third, the literature review exposed a tension in current thought regarding the role of conscience in healthcare. On one side, writers such as McLeod (2010) argued that the healthcare professional’s exercise of conscience jeopardizes the patient’s autonomy because the patient may be overwhelmed by having a person in a position of power disagree with her. On the other side, writers such as Pellegrino (2008) argued that the consciences of healthcare professionals benefit patient autonomy by ensuring that the relational dimension of conscience remains active. In keeping with the work of authors such as Goodpaster (2007), this active and externally-oriented conscience can also benefit society by contributing to the corporate consciences of healthcare

institutions. The research contained in this dissertation provides further insight into the role of conscience in healthcare.

### **Dissertation Methodology and Methods**

This dissertation used a narrative inquiry methodology to analyze the deliberative processes of the Saskatoon Health Region (SHR)'s Palliative Care Services team. Following approval from the Behavioural Research Ethics Board of the University of Saskatchewan and operational approval from the Saskatoon Health Region, my research was conducted in three phases.

In the first phase of my research, I conducted twelve interviews and one focus group with members of the palliative care team. Each session was approximately one hour in duration, and each session was recorded and transcribed. Following the withdrawal of one participant, the transcripts of eleven of the interviews and the focus group were analyzed using open and axial coding to identify themes in the palliative care team members' perceptions of their individual and collective deliberative processes.

In the second phase of my research, I presented the findings from the first phase to two interpretive panels. Each interpretive panel brought together four experts from the SHR's senior management and leadership who commented on the findings, paying particular attention to their implications for policy development in other areas of the healthcare system. These panels were each approximately one hour in duration, and each session was recorded and transcribed. The transcripts of both sessions were then analyzed using open and axial coding to identify themes in the interpretive panel's comments. The findings from the first two phases were presented in Chapters Four, Five and Six of this dissertation.

In the third phase of my research, the findings from the first two phases will be used to answer the four research questions that have guided this dissertation. The findings of my research will then be discussed in the larger context of the literature reviewed in Chapter Two.

### **Responses to Research Questions**

As indicated, the research presented in this dissertation was conducted to answer four research questions. In this section, I respond to each of these questions by drawing on the findings presented in Chapters Four, Five and Six. This will be followed by a discussion of the findings in the context of the literature reviewed in Chapter Two.

#### ***Research Question #1: What are the experiences of team members who have been directly involved in decisions that engage their consciences within the culture of palliative care?***

In my interviews with members of the palliative care team, I intentionally minimized my use of the word ‘conscience.’ Instead, I prompted interviewees to describe their deliberative processes by asking them to share examples of situations where they experienced a disagreement with a patient or where they felt moral distress. As shown in the evidence presented in this dissertation, this approach proved successful, as I was able to tease out the role of conscience implicit in the narratives shared by participants.

The experiences shared by team members involved a diverse range of situations such as patient placement, terminal sedation, caring for patients with drug addictions, and physician-assisted death. In addition to these more ethically charged situations, team members shared routine scenarios. For example, when asked directly what role her conscience played in her care of patients, one participant described her decision regarding whether or not to provide care for a patient before leaving for a break. As I listened to these stories, I observed that the palliative care



team members routinely engaged their deliberative capacities to judge whether their patients had received the care they needed.

As shown in Figure 7.1, below, I propose that this use of their consciences stemmed from the team members' capacity for reflection, which triggered the engagement of their consciences in situations where team members felt their patients deserved better care. A healthcare professional's capacity for reflection may lead her to consider the needs, opinions, beliefs and values of her colleagues and the patient and his or her family, as well as her personal, professional and institutional values. The arrows in figure 7.1 show that in the context of healthcare decision-making these factors, combined with factual information regarding the situation in question, enable the healthcare professionals's conscience to make a judgment about which course of action is ethically best. The healthcare professional may then either ignore this judgment or attempt to follow through on it, which may or may not be successful. Failure to follow through on the judgment of conscience, particularly when the healthcare professional sincerely wants to carry it out but is prevented from doing so by institutional constraints, may lead to moral distress.

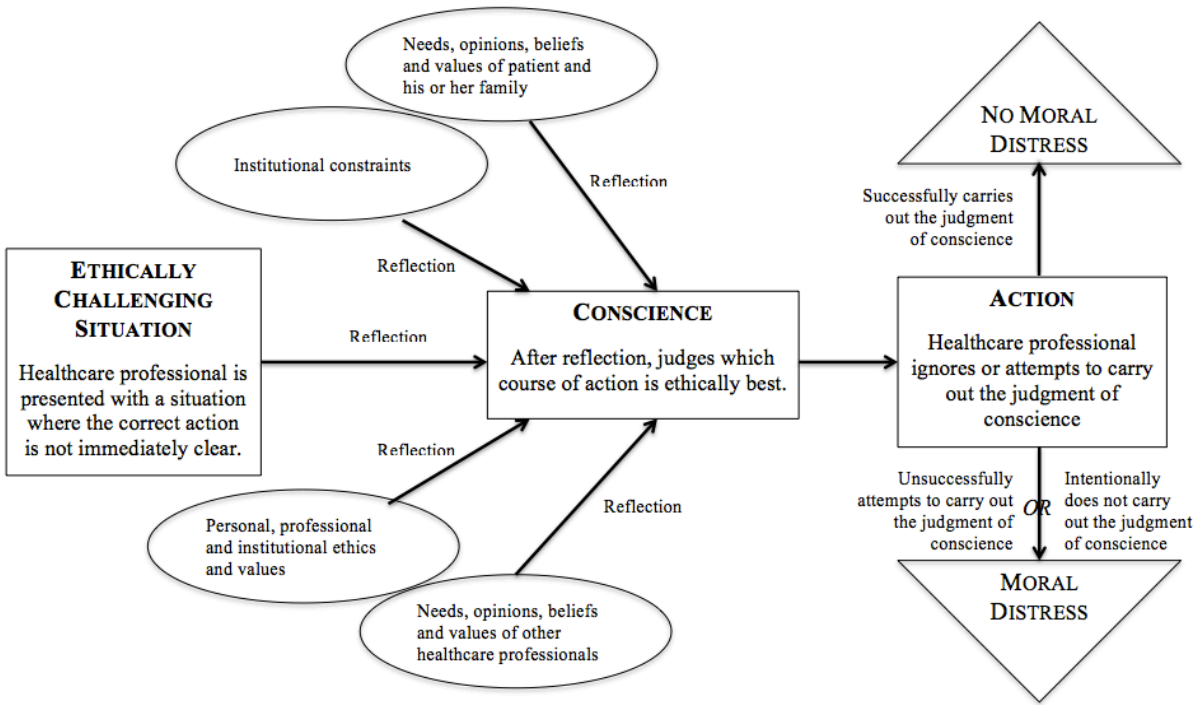


Figure 7.1: Exploratory Heuristic on the Role of Conscience in Ethical Decision-Making

For example, consider the story shared by one participant regarding a situation where she was unable to follow through on the judgment of her conscience. The team member shared that she was caring for a patient who wanted to return to his home community to die; however, due to the scheduling requirements of the ambulance, the patient could not return home. This presented the healthcare professional with an ethically challenging situation: Should she respect the rules that govern ambulance scheduling, or should she fight to get her patient back home? In her telling of the story, the participant related her reflections on the psychosocial needs of her patient and her decision that she needed to do every thing she could to help the patient get home. As presented in Figure 7.1, I propose that the healthcare professional's reflections led to her judgment of conscience, namely, that she must attempt to bend the rules to get her patient home. In this situation, the healthcare professional was ultimately unable to carry through on this

conviction, and she shared the moral distress she felt due to the institutional constraints she had experienced.

This description of the role of conscience is consistent with the literature that understands “ethical reflection” and “moral reasoning” to be distinct from the judgments of conscience. For example, the distinction between reflection and conscience provided above coincides with Bebeau, Rest and Narvaez’s (1999) distinction between moral sensitivity and moral judgment. However, many of the stories shared by participants also supported Callahan’s assertion that, “in real life, it often can be difficult to tell where seeking and searching end, and finding and deciding begins” (1991, 21). For example, the participant who stated that she used her conscience to decide whether to tend to her patient before leaving for a break did not distinguish between her reflections and her judgment that she should stay with her patient. In their stories, few participants could pinpoint the exact moment that they arrived at an ethical judgment; rather, many of them presented the reflections that led up to the decision and the decision itself as one event.

Self-reflection was both explicitly commented on and implicitly present in the stories shared by participants, particularly in narratives that emphasized the conscientious care provided by the team. The palliative care team members’ capacity for self-reflection was also highlighted by members of the interpretive panels and is in keeping with Schon’s (1984) concept of the reflective practitioner. The value of self-reflection and other tools used by team members in situations that engaged their consciences are further described in the response to Research Question #3.

***Research Question #2: How do palliative care providers describe the deliberative processes used at personal, professional and team levels, regarding end-of-life care?***

In my research, palliative care participants described their deliberative processes as a blend of the characteristics, skills, tools, practices and mindsets that are shared by team members as they navigate the complexities of patient care at the end of life. In Chapters Four, Five and Six, I grouped these tools into five themes that captured the deliberative processes used by palliative care team members: clear communication, a collaborative team approach, holistic care, real relationships, and engaged consciences. Each of these themes is present at the personal, professional and team levels of decision-making.

At the personal level of decision-making, most team members focused on the natural abilities that made them a good fit for palliative care. For example, some team members described their communication skills, while others focused on their sense of self-awareness, ability to reflect on their actions, conscientious work ethic and leadership skills. In their discussions of the palliative care team, members of the interpretive panels agreed that the palliative care team draws a certain type of person. This conclusion was supported by the findings gathered from the palliative care team, as each of the eleven team members either explicitly stated that they felt they were working with a unique team, or implicitly emphasized their appreciation for their team members in the stories they shared. Further, in my assessment, the palliative care team members that I interviewed seemed well suited to their work because each of them either explicitly described their personal commitment to the delivery of holistic care, or carried this theme implicitly in the stories they shared. For example, when asked to describe palliative care, almost every participant stated, in what I interpreted to be a proud manner, that palliative care used a holistic approach to patient care. I interpreted this pride as a

signal that these participants had taken ownership of the goals of palliative care, and that at a personal level their deliberative processes were oriented toward the provision of holistic care.

In their reflections on their innate qualities, most team members also made either an explicit or an implicit reference to their ability to form relationships with their patients. When asked to comment on these relationships during their focus group, the participants emphasized several tools that helped them to cultivate these relationships, which included establishing trust and maintaining honesty. However, some participants also acknowledged that it was challenging to determine how much of their own personality, opinions, beliefs and values to share with patients, and through my own observations, it seemed that determining the right level of honesty was a matter of personal moral judgment. Several participants also expressed a commitment to personal integrity, and, in my observation, this commitment may have compelled them to follow the judgments of their own consciences. This observation is consistent with Carter's (1997) description of integrity, which also focused on an individual's commitment to act on their discernment of right or wrong. At the personal level of decision-making, I understand the team members' deliberative processes to have been rooted in their integrity (i.e., their commitment to acting on what they have discerned is right or wrong), which in turn required them to use tools such as self-reflection and honesty to build the relationships needed to provide their patients with holistic care.

At the professional level of decision-making, the team members interviewed described the skills they had developed during their training and over the course of their careers, many of which blended with their personal and team deliberative processes. For some, this included active listening skills, while for others their primary focus was on their ability to work as part of an interdisciplinary team. Notably, the unanimous personal commitment to holistic care

discussed in the preceding paragraphs extended to participants' professional commitment to patient-centred, process-oriented care. In their interviews and focus group, the palliative care team members concluded that their success in providing holistic care was often aided by the extra flexibility in time and space given to palliative care services. Members of the interpretive panels reinforced this observation. However, one interpretive panel member also stressed that trust can be established with patients in a brief period of time if healthcare professionals are willing to participate in an honest discussion of the goals of care. In my own assessment, it seems that while the palliative care team certainly benefits from having a welcoming space and a lower patient-to-staff ratio than many other areas of healthcare, they also relied on other tools that promote an environment that fosters the healthcare professional-patient relationship, such as active listening skills and honesty concerning the goals of care.

In the comments and stories shared by participants, I observed that maintaining professional boundaries when developing authentic relationships with patients required support from trusted team members and a threshold of self-awareness on the part of healthcare professionals. In my assessment, conscience played a critical role in determining what constituted a healthy relationship among healthcare professionals and patients, as the former continuously judged the morality of their actions within the context of these relationships. For example, one participant shared that although she needed to form a relationship with her patients, she also needed to use her moral judgment to ensure she did not become inappropriately involved in her patient's story. Other team members shared that they relied on advice from their team members when faced with an ethical decision. From the insights I gained from the palliative care team, I conclude that the professional level of decision-making drew on the

healthcare professional's conscience (i.e., her moral judgment), and required support from many other tools, including a supportive team and an environment that facilitates trusting relationships.

At the team level of decision-making, participants unanimously praised the effectiveness of their collaborative approach to patient care. Team members cited a number of tools that contributed to this collaborative teamwork, including the regularity of team meetings and the open dialogue between team members. Some team members stated that the team was strengthened by deliberative team building efforts, while the stories of other participants showed that the team benefited from the communication skills of individual team members. Many participants stated that they valued the interdisciplinarity of palliative care, and this interdisciplinarity contributed to each team members' ability to take ownership of the care the team provided to patients. For example, although the palliative care physicians were ultimately responsible for all medical decisions regarding their patients, in the stories shared by participants, I observed that their leadership provided a space for all team members to participate in decision-making concerning patient care.

Several participants also stated that the team's successful provision of holistic care was due in large part to their focus on articulating the goals of care with patients. In addition to signaling to patients and families that palliative care is distinct from most acute care services, I observed that these clearly articulated goals helped team members to function as a unit. This coincides with Wilson's (1991) assertion that the members of successful organizations share "a sense of mission" (26) that is focused on the completion of a critical task. I suggest that providing holistic care is the critical task of palliative care, which has enabled the team to form a common mission and motivated their collaboration. Some participants also credited the personal and professional relationships they had built with each other as a contributing factor to their

overall success as a team. In my view, these relationships were rooted in their commitment, both as individuals and as a team, to providing high quality holistic care. Building on the tools used at personal and professional levels of decision-making, the deliberative processes of the palliative care team are nested in their commitment to provide quality holistic care for their patients.

The comments and stories of the palliative care team members who participated in my research showed that at personal, professional, and team levels the deliberative processes of the palliative care team relied on clear communication, collaborative team work, a holistic approach to care, real relationships, and engaged consciences. Each of these overarching themes contained specific tools that were useful in different situations, and in situations that involved a conscientious disagreement some of these tools were more prominently used than others. The tools used to positively resolve conscientious disagreements are the subject of Research Question #3.

***Research Question #3: What part of the deliberative processes described by palliative care team members contributes to the successful mediation of conscientious disagreements between healthcare professionals and patients, as perceived by the healthcare professionals?***

In their interviews and focus group, palliative care team members identified several tools that contributed to the successful mediation of conscientious disagreements between healthcare professionals and patients. These tools are interwoven throughout the themes that emerged during the data analysis, as presented in Chapters Four, Five and Six: clear communication, collaborative teamwork, a holistic approach to care, real relationships, and engaged consciences. Although all participants from the palliative care team initially focused their responses on more easily observed tools such as those categorized under clear communication, collaborative teamwork and holistic care, it became evident to me that in times of conscientious disagreement,



their deliberative processes were deeply rooted in tools related to the formation of real relationships and the participants' engaged consciences.

As presented in Figure 6.1, engaged consciences form the often-unseen root of palliative care team members' deliberative processes. When prompted to share stories that had an ethical dimension, some participants focused on disagreements with patients and their families, while others related a situation that led to moral distress for the storyteller. In these stories, the consciences of participants were implicitly present as they described their moral reasoning, and from these descriptions I was able to form a definition of conscience that was accepted by the palliative care team's focus group. In this definition, conscience was described as having three facets: a facet that helped healthcare professionals to determine right from wrong; a facet that compelled them to work in a conscientious manner; and a facet that helped them to navigate challenging situations. Collectively palliative care team members' responses described these three facets as being inseparable, and many participants firmly stated that they would not be able to leave part of their conscience at home without abandoning the other facets. For example, one participant shared that if she was not able to follow through on her judgments of right and wrong, she would likewise be unable to form the connections with her patients that she needed to provide conscientious care.

Further, through the stories shared by participants, I observed that team members required a high degree of self-awareness to fully engage their consciences in their work, a skill that I witnessed as participants articulated their thought processes and reflected on their own actions. These observations are consistent with the emphasis placed on moral reflection by Bebeau (1995) in her description of the moral reasoning of professionals in scientific fields. In agreement with Bebeau that professional codes of conduct are incapable of addressing the

complex situations that develop due to changing technologies and societal norms, I suggest that the palliative care team members' reliance on their own reflections was necessary because they found themselves in situations that were more complex than a code of ethics could anticipate or describe. This is supported by my observation that throughout this research, participants did not list their professions' code of ethics as a tool in their decision-making processes. However, it should also be noted that participants were not prompted to discuss their professional code of ethics, and that many still referred to their responsibilities as a physician, nurse, etc. when describing their care for their patient. I propose that while a code of ethics may provide a standard for professional responsibilities, the self-reflection of team members makes them aware of the judgments of their consciences and provides them with the insights they need to act in a manner that will benefit their patients. This is in keeping with the comments made by several interpretive panel members who reinforced the link between self-awareness, conscience and patient care. However, contrary to Bebeau's assertion that reflective skills can be developed, one panel member expressed her opinion that self-awareness is an innate characteristic that cannot be learned. The research presented here cannot resolve this dispute, but, as will be discussed in Section C of this chapter, these findings do suggest some implications for healthcare professionals.

In the palliative care team members' description of conscience and stories concerning ethically challenging situations, I observed that their consciences included what Visher (2010) described as a relational dimension. For example, every participant related a story in which they considered the impact their actions would have on both themselves and those in their care. In addition to considering the outward impact of their actions, team members also related the influence that others, their team members in particular, had in their deliberative processes.

Several participants shared that they had sought out the opinion of their colleagues when they were faced with an ethical decision and shared stories about situations in which a colleague had played a key role in helping them to determine the right course of action. In my assessment, the participants' descriptions of their actions and their deliberative processes are consistent with Visser's assertion that the conscience is both formed and expressed in relationships.

In their discussion of conscience, focus group participants came to a consensus that their engaged consciences and their commitment to live as persons of integrity had a positive effect on their relationships with patients, families and other healthcare professionals. This is consistent with my insights gained from the stories shared by participants in their interviews, which demonstrated that when faced with ethical challenges, team members were committed to working through conscientious disagreements in a manner that safeguarded their relationships with patients. For example, several team members stressed the importance of maintaining an open dialogue with patients and clearly communicating the team's goals of care to ensure they aligned with the patient's personal goals of care. As some team members reported, these discussions required healthcare professionals to be honest with their patients, with one participant in particular clearly stating that she believed that it would be harmful to the patient if team members were dishonest about their ethical judgments. Other team members shared this sentiment, although they also observed that there are varying degrees to the truths shared with patients, particularly concerning institutional issues such as patient placement. For their part, many members of the interpretive panels echoed the importance of honesty and trust in relationships, although one panel member repeated the palliative care team's caution that there are degrees of honesty that must be navigated by healthcare professionals. The value of honesty, as it was presented by participants in my research, is consistent with Pellegrino's (2008)

assertion that patients benefit from hearing the true opinions of their healthcare professionals. However, in my own assessment the exact nature and degree of this honesty remains unclear.

When describing situations that engaged their consciences, the holistic care of patients continued to be at the centre of team members' descriptions of their deliberative processes. In the stories shared by participants, I observed that their provision of holistic care in ethically challenging situations was bolstered by the team's ability to collaborate and communicate clearly in these situations. For example, as mentioned in the response to the previous research question, the team members' skills as communicators allowed them to clearly state the goals of palliative care in a manner that did not alienate those in their care. Many of the stories shared by participants demonstrated that at times of conscientious disagreement, this helped them to uncover the underlying causes of conscientious disagreements among team members and between the team and those they cared for. Further, several participants noted that the collaborative approach shared by the team helped individual team members to manage their moral distress and provided patients and families with the perspectives of several healthcare professionals to aid their deliberative processes. All members of the interpretive panels agreed that clear communication and collaborative teamwork supported the provision of holistic care in situations that engage the consciences of healthcare professionals, an observation that is supported by my own insights and is, to the best of my knowledge, uncontested in the literature.

Through the comments and stories shared by palliative care team members, I observed that their deliberative process were rooted in the consciences of individual team members, particularly in situations that include an ethical dimension. In my view, the consciences of the healthcare professionals interviewed in my research both support and are supported by a web of relationships that includes other healthcare professionals, patients and families. Both the

palliative care team members and the interpretive panel participants agreed that relationships are necessary for the provision of care that tends to the needs of the whole patient, which is in turn further supported by team collaboration and clear communication. Of the five themes outlined in this dissertation, the tools connected to the engagement of consciences and the formation of relationships were, in my assessment, the most useful for members of the palliative care team as they addressed ethically challenging situations.

***4. What aspects of palliative care providers' deliberative processes provide insights that inform the development of policy and/or reflections on the practices of professionals in other areas of the healthcare system?***

Responses to Research Question #4 were provided by both the palliative care team and the interpretive panels, the latter focused their comments on the five themes detailed in Chapters Four, Five and Six: clear communication, collaborative team work, a holistic approach to care, real relationships, and engaged consciences. While there are differences between palliative care and other areas of the healthcare system, many of the tools found in these five themes provide possible insights such as may inform the development of policy and/or reflections on the practices of professionals in other healthcare settings beyond palliative care services.

Both the palliative care team members and the interpretive panels felt the tools used by the palliative care team to enhance holistic care through clear communication and collaborative teamwork were potentially transferable to other areas of the healthcare system. Although they acknowledged that lower staff to patient ratios and physical space constraints limit other healthcare teams, both groups of participants maintained that communication skills could be developed, particularly during training, to facilitate discussions regarding the goals of end-of-life care. Concerning collaborative teamwork throughout the healthcare system, both the palliative

care team and members of the interpretive panels recognized the challenges facing large healthcare teams who are spread across multiple sites. As a resolution to these challenges, one interpretive panel member proposed the creation of microsystems, which divide larger teams into multiple sub-teams, as a means for promoting teamwork, ensuring co-location, and fostering regular collaboration amongst healthcare professionals within their sub-teams. Additionally, another panel member stressed the theme of holistic care by reiterating the value of using the whole care team to create care plans that consider the patient's life outside the hospital.

Although the palliative care team and the interpretive panels agreed that practices that promote clear communication and collaborative teamwork have the potential to improve the provision of holistic care, during the second interpretive panel there was some discussion about whether there is only one way to provide holistic care. One participant stated that team collaboration and holistic care look different in different healthcare disciplines. This statement was not contested by other panel members. In my view, it seems that the goal should not be to create teams in other areas that are identical to the palliative care team, but rather to create an environment in which healthcare teams can develop the practices that they need to create a collaborative environment such as best suits the care provided in their areas, an assertion that has implications for healthcare institutions and future research (see section C).

In addition to their insights regarding the adaption of clear communication, collaborative teamwork and holistic care for other areas of the healthcare system, participants in my research unanimously agreed that the development of authentic relationships among healthcare professionals, patients and families has the potential to facilitate the provision of holistic care beyond palliative care. Several palliative care team members described their relationships with their teammates and those in their care as being rooted in trust. Although palliative care

participants were aware of the time limitations present in most areas of the healthcare system, they felt that trust might be established quickly in the context of an organizational culture that placed value on clear communication and collaborative teamwork. This suggestion was supported by the interpretive panel members, many of whom felt that the culture of the healthcare system was beginning to place a greater value on relationships, with one participant providing an example in the Health Region's emphasis on co-production (i.e., collaboration between healthcare professionals and patients and families). However, panel members also discussed the barriers that make it difficult to promote an environment that fosters relationships. For example, members of the second interpretive panel discussed the inherent difficulty of developing the skills necessary for collaborative teamwork when their students' learning environment (i.e., the healthcare system) does not value these qualities. The panel members involved in this discussion seemed to believe that the cultural shift needed to develop and maintain relationships would require a coordinated effort between educational and healthcare institutions.

The interpretive panel members also agreed with the palliative care team participants' assessment that the authentic relationships formed in the context of healthcare required healthcare professionals to bring their whole selves, including their consciences, to their work. Several interpretive panel participants stressed the importance of creating policies that encourage self-awareness in healthcare professionals; however, as mentioned in the response to the Research Question #3, there was disagreement among panel members regarding whether the capacity for self-reflection is an innate quality or something that can be taught. Interpretive panel members also discussed the importance of helping healthcare professionals to find coping mechanisms, with one participant stressing that healthcare professionals need to take ownership

for managing their moral distress. Although both panels felt that healthcare institutions could potentially form policies that support the five themes outlined in my research, the second interpretive panel ended their session with a discussion of the value of limiting policy interventions that constrain the actions of healthcare professionals, focusing instead on giving healthcare professionals the freedom they need to be engaged in their work. For example, several participants criticized policies that focus on getting patients out of the hospital, saying that the financial messaging communicated by the Health Region can have the unintended consequence of lowering the healthcare team's engagement with patients. Rather than focusing on financial concerns, healthcare institutions could instead focus on promoting relationships, which could improve patient care and patient flow. This focus on freedom is consistent with Wilson's (1991) assertion that successful organizations require an appropriate degree of autonomy to pursue their mission.

In my research, palliative care team members and interpretive panel participants agreed that although the palliative care team benefits from several advantages not present in other areas of the healthcare system, other healthcare teams might benefit from policies and practices that promote the five themes identified in this dissertation. Several members provided examples of initiatives that could improve patient care, including the formation of microteams and staff education to help healthcare professionals develop their own coping mechanisms and reflective abilities. Members of both interpretive panels also discussed the importance of health sciences education, with some members suggesting that the development of the skills required to provide quality patient care needed to be a coordinated effort between educational and healthcare institutions. All participants in my research described conscience as an asset to healthcare professionals, and some interpretive panel members proposed that healthcare professionals might



be best suited to manage their own moral judgments and moral distress with support from policies that foster relationships, rather than the imposition of constrictive, top-down policies. In the following section, I will discuss these responses to these research questions in the broader context of the related literature.

## **B. Discussion of the Findings**

The responses of both the palliative care team and the interpretive panels provide several insights into the role of conscience in healthcare. In this section I will discuss three main areas of interest arising from the findings and the literature: first, the faculty of conscience and its role in maintaining integrity; second, the relational dimension of conscience in healthcare professional-patient relationships; and third, the organizational culture of healthcare institutions.

First, having heard and analyzed the stories shared by palliative care team members, I observed that the three facets of conscience as described by participants are compatible with the definition of conscience employed in this dissertation. In Chapter Two, I outlined my reasons for defining conscience as a judgment about the morality of an act, exercised externally to preserve the integrity of the moral agent. Participants in my research did not address this definition directly, but rather they provided descriptions of three inseparable facets of conscience: conscience as something which determines right from wrong; conscience as something which spurs persons to behave in a conscientious manner; and conscience as something that helps moral agents to navigate challenging ethical situations. In both the definition of conscience and the three facets, the moral agent must rely on her conscience to determine what constitutes right action and cannot separate the judgments of her conscience from her own actions if she is to maintain her integrity. Although articulated in different ways, the definition explicated in Chapter Two and the description provided by palliative care team members are commensurate.

Further, in Chapter Two, conscience was distinguished from moral reflection. In my research, the distinction between the two is less definitive, as the first facet of conscience corresponds to conscience as a judgment, while the third facet's emphasis on navigation seems to incorporate moral reflection with moral judgment. As mention in the response to Research Question #1, this is not surprising in light of Callahan's (1991) reflection that in practice these two functions are often inseparable. The second facet of conscience meanwhile emphasized conscientious behaviour, and of the three facets it is the most strongly correlated with the need for acting on the judgments of conscience.

As observed in this second facet of conscience, participants in my research and the scholars represented in the Chapter Two literature stressed the importance of integrity in their descriptions of conscience. As depicted in Figure 7.1, I observed that participants' greatest sources of moral distress were situations wherein they felt that they could not act on their own ethical judgments, whether these situations were the result of institutional constraints or conscientious disagreements. The distress experienced by participants was in keeping with Carter's (1997) emphasis on the moral agent's need to act in accordance with the judgments of conscience to preserve integrity. There is also a similarity, as well, with Vischer's statement that "the exercise of conscience is not just an expression of a person's identity; it is a means by which a person's moral identity may become fully and coherently formed" (2010, 71). Based on this dissertation research and the extant literature, integrity appears to be required for the full flourishing of the individual, and this is no less true for healthcare professionals who must balance their own values with those of their patients and their colleagues. By maintaining their own integrity, healthcare professionals are able to manage moral distress, which, as Burston and

Tuckett (2012) have shown, promotes professional conduct and improves the organizational culture of institutions.

Although integrity is consistently described in the literature as the ability to follow through on the judgment of conscience, it remains unclear whether damaging one's integrity would have a negative impact on one's ability to engage in moral reasoning or to form moral judgments. For example, consider the work put forward by Bebeau, Rest and Narvaez (1999) who identified four components of morality: moral sensitivity, moral judgment, moral motivation, and moral character. In the language employed in this dissertation, moral reasoning and reflection roughly correspond to moral sensitivity, conscience to moral judgment, and integrity incorporates components of what Bebeau, Rest and Narvaez called moral motivation and moral character, both of which are involved with following through on the judgments of conscience. In their study of the four components of morality, You and Bebeau (2013) presented evidence that suggested that the different components of morality are independent from each other because a person's score on one of these components has no predictive value for determining their score on the other components. However, despite You and Bebeau's claim that the components of moral reasoning are independent, most participants in my research emphasized that the components of their conscience were interdependent. This finding suggests that although the characteristics measured by You and Bebeau may not directly correlate with each other, it is still possible that they are related to each other within individual persons. For example, while the capacity for self-reflection may not guarantee that an individual is committed to living an integral life, it is still possible that being prevented from living an integral life would damage one's capacity for self-reflection. Researching this hypothesis would require a study that

follows one participant over time to determine if weakening one moral component has an effect on the other components.

As a second point of interest, the findings of my research are also consistent with the related literature on the relational nature of ethical decision-making. In their descriptions of situations that engaged their consciences, many participants emphasized that they sought input from their team members as well as from the patient and his or her family. Several participants stated that these consultations required them to have formed authentic relationships with their colleagues and those in their care, such that these relationships were a critical component of the palliative care team's deliberative processes. This supports Vischer's concept of the relational dimension of conscience, which claims that the conscience is formed in a web of relationships and impacted by other individuals, as well as Downie and Llewellyn's (2008) concept of the *relational self*. The relational self understands individuals to be enmeshed in both positive and negative relationships that influence a moral agent's autonomy (i.e., their capacity for decision-making). In the comments and stories shared by participants in my research, I have observed that from the healthcare professional's perspective, it is possible for them to form authentic relationships that have a positive influence on the autonomy of those in their care. Several team members stated that these relationships required trust, honesty and an institutional environment that fostered the formation of relationships; however, it remains unclear whether patients and families would present a similar description of their relationships with healthcare professionals. Although, the FAMCARE study conducted by the palliative care team five years prior to my research indicated that 79.5% of families were satisfied or very satisfied with the way they were included in treatment and care decisions (see Appendix D), more research is needed to determine

whether, from the families' perspectives, this satisfaction was influenced by the tools discussed in this dissertation.

The description of positive relationships presented in this dissertation provide insight into a major tension observed in the literature reviewed in Chapter Two concerning the expression of conscience in the healthcare professional-patient relationship. Agreeing that there is a power imbalance in this relationship, scholars such as McLeod (2010) and Pellegrino (2008) were in disagreement over whether conscience is a useful tool to help a healthcare professional maintain a positive influence on those in her care: McLeod contended that patients are harmed when healthcare professionals articulate their conscientious objections, while Pellegrino maintained that patients benefit when the healthcare professionals who care for them articulate their objections. As detailed in Chapter Five, the healthcare professionals interviewed for my research emphasized that honesty (i.e., respectfully articulating the reasons for their objection to particular treatments) was crucial to the formation of authentic relationships. For example, when asked about the role of honesty in her relationships with patients, one participant shared, “you injure a person if you’re not being truthful with them” (FG I2 00:58:26) and explained that being honest with patients helps to establish and maintain trust. Other participants related numerous situations in which they clearly and respectfully communicated a patient’s terminal prognosis and the goals of palliative care even if this was not what the patient or their family wanted to hear. However, some participants also cautioned that there were varying degrees to their honesty with patients and that they were careful to only share the parts of their judgments that they felt were useful for patients to hear. In my own assessment, the palliative care team’s emphasis on honesty supported Pellegrino’s assertion that, “patients especially need the input of others if their own choices are to be genuine ones” (207–208). However, I also acknowledge that without the finesse exhibited

by participants in my research regarding the quantity and manner of sharing, this honesty could potentially be harmful for patients. Although my research provides insight into ways that these potential harms could be mitigated (see the following paragraph), it must be noted that a full analysis of McLeod's position that conscientious objectors harm their patients would require further research into the experience of patients and families at times of conscientious disagreements.

Mindful of the centrality of the healthcare professional-patient relationship in the provision of holistic care, I proffer that the tools presented throughout this dissertation have the potential to help healthcare professionals to find ways to maintain positive, authentic relationships that support patient autonomy. As unanimously agreed upon by the participants in my research, tools such as those grouped under clear communication and team collaboration are indispensable to healthcare professionals who provide holistic care. Further, many participants in my research, both palliative care team members and members of the interpretive panels, emphasized that ideally, healthcare is delivered in a web of positive relationships that function to continuously improve patient care. The key role of relationships and the tools associated with them, such as trust and honesty, is supported by research on relationship-centred care (Beach et al. 2006) and Chochinov's (2013) "model of therapeutic effectiveness," which emphasize the value of genuine relationships in healthcare. In regards to conscience, the final theme identified in my research, I propose that rather than pitting the values of healthcare professionals against the values of patients and families, conscience is a tool that can help healthcare professionals to navigate the conscientious disagreements that inevitably arise in the context of end-of-life decision-making and to determine how best to maintain honesty in a manner that respects the values of their colleagues and those they serve.

The palliative care team's description of the role of conscience in their work also leads to a third area of interest: the intersection of my research with Goodpaster's *culture of ethical awareness* (2007). As mentioned above, the findings of my research evidence that participants' consciences had a relational dimension that was influenced by the needs, opinions, beliefs and values of their colleagues and those in their care. This relational dimension extended into the culture of the palliative care team, which several participants described as being centered on the team's provision of holistic care. Collaborative teamwork formed the heart of this culture, as throughout their interviews participants repeated that they drew on their team for support, both personally and professionally. For example, one participant explained how her team helped her to reflect on the care she provides for patients:

There will be situations that perhaps touch us positively or negatively throughout the time based on whatever that situation is and I think it's a safe place to have conversations about, "how are we impacted?" as well. So a recognition I think that we come into families lives and into their circle, this very intimate and special - or significant time, anyways. [...] How do we have a space where we can try to support each other and be aware of what our own stuff is that we bring? [...] So, each of us might have a patient or a family member that particularly touch us for some reason, or that perhaps we struggle with a little bit more, or other, so it's nice to have that team support so that not one person carries or owns the success or the failures of that piece. (I2 00:08:01)

This emphasis on reflection and shared decision-making within the team was echoed by several other participants, one of whom clearly expressed the value of reflecting on situations as a team when she simply stated, "talking through [a situation] sometimes is enough to get you a better understanding" (FG I11 00:28:43). This reflective and collaborative culture was a source of pride for several participants, who linked their culture to the team's provision of conscientious care. For example, one participant highlighted her team's commitment saying, "I don't know a more conscientious team that I'm privileged to work with" (FG I12 00:29:02). This commitment extended to forming relationships with those in their care, as, for example, another participant

stated, “[on this team] I don’t think you ever hear, ‘I don’t have time to find out who that person or who that family is’” (FG I2 01:10:08). Although participants did not agree about whether this culture was unique to palliative care, they agreed that the culture of palliative care provided an environment that fostered ethical reflection and shared decision-making, which I consider to be commensurate with Goodpaster’s culture of ethical awareness.

The tools found throughout the five themes presented in this dissertation reinforced the culture of ethical awareness of the palliative care team. Open communication can be singled out as one tool that unlocked the team’s ability to collaborate, engage in reflections on their individual and team performance, and make ethical decisions. As one participant shared,

A lot of it comes down to having a place where there's space for open communication and a difference of opinion. So it is safe to disagree. [...] I think that we try to - as much as possible - have that discourse, discussion, disagreement, at the front end so that we can have our piece heard or said, and then once a decision is made try to support it and try to make it the best possible piece. (I2 00:45:46)

This open communication becomes all the more important when considered within the framework of exit, voice and loyalty presented by Hirschman (1970). Hirschman proposed that organizations can only be made aware of the need for change if their members are able to exit the organization or voice their concerns. Since few Canadians can leave our healthcare system because they do not have the finances required to go to another country, (i.e., they cannot exit), it is important to maintain open communication that allows healthcare professionals and users of the healthcare system to voice their conscientious objections and agreements in a respectful manner. For example, several times throughout their interviews, palliative care team members noted their frustration with the patient placement system; the Health Region’s leadership would benefit from hearing these concerns because it may provide them with the insights they need to improve this system. Conversely, if healthcare professionals, patients and families have no



avenue to voice their concerns, the Health Region's leadership will have no way of knowing that there are problems with the patient placement system. Open communication also serves the Health Region by ensuring that teams can engage in ethical decision-making together, reinforcing what Goodpaster termed "the corporate conscience."

In addition to the practical and relational benefits noted above, findings from my research suggest that allowing healthcare professionals to give voice to their conscience concerns will encourage them to contribute to the continuous improvement of the healthcare system. For example, several team members described situations in which the team was able to find a creative solution in a difficult situation. One team member described such a situation, sharing a story about the team's efforts to help a patient return home. Allowing healthcare professionals to voice their concerns can have the added advantage of alerting senior leadership of problems as they arise. For example, one participant shared her concern about the cost of futile treatment for the healthcare system, and her understanding of herself as a steward of scarce resources. This participant's image of herself as a steward can also be linked to Hirschman's concept of loyalty. Hirschman describes loyalty as being a characteristic that "holds exit at bay and activates voice" (78), and in the case of the healthcare professionals interviewed for my research, I offer that their loyalty to the Health Region also helped them to remain committed to the service of others. This link between voice, loyalty and conscience is supported by the comments made by members of the interpretive panels. For example, one participant stressed that the Health Region must actively help healthcare professionals to avoid compassion fatigue and moral distress, as these can lead to low work attendance, burnout, and the disengagement of one's conscience from the workplace. I echo the conclusion voiced by members of the second interpretive panel, who stated that the Health Region will likely benefit from forming policies that provide frontline healthcare

professionals with the freedom they need to engage their consciences in a culture of open communication. I suggest that this will contribute to the development and maintenance of the corporate conscience that is at the heart of Goodpaster's culture of ethical awareness

This discussion has focused on three key areas of interest that are informed by the research presented in this dissertation. First, the descriptions of conscience shared by participants are consistent with the predominant threads in the literature that identify conscience as a key component of integrity and human flourishing. My research has made a significant contribution to understanding the relationship between moral reflection, conscience, and action, all three of which function together to avoid moral distress. Second, the findings support Vischer's understanding of the relational dimension of conscience and the importance of maintaining honesty in healthcare relationships. Although my research is not definitive, it supports the assertion made by Pellegrino and others that patients benefit from clear communication with healthcare professionals who are committed to maintaining their personal integrity. Third, the findings also support extending Goodpaster's notion of a culture of ethical awareness to the context of the Canadian healthcare system. My research has detailed the culture of ethical awareness found on the palliative care unit and presented an argument favouring open communication as a means of ensuring that the Health Region's leadership is made aware of any need for change in the institutions that govern Canadian healthcare. In the following section, I will discuss the implications of these findings for institutions, healthcare practitioners, patients, and future scholarship in this field.

### **C. General Implications of my Research**

The research presented in this dissertation provides insights into the situated role of conscience in the web of relationships in which healthcare decisions are made. While much of

the literature on conscience tends to be centred on the individual's conscience, often isolated from the context in which she lives, my research has inquired into the culture of palliative care to describe the relational dimension of conscience. The findings of my research suggest that the individual and collective manifestation of conscience was influenced by moral reflections that considered the needs, opinions, beliefs and values of others beyond the agent herself. This is reinforced by the claim of Carter (1997) and others that the judgments of conscience must be followed through to preserve the moral integrity of the agent. Further, in my analysis of the comments and stories shared by members of the palliative care team, I observed that conscience is both influenced by and influences the environment external to the individual, being formed by and forming a culture that is sensitive to ethical challenges as they arise. My research has uniquely described the value of collaborative ethical decision-making for both the healthcare professional and the organizations of which she is a part, proposing that conscience and the tools that facilitate its respectful engagement could improve the delivery of care throughout the healthcare system. The following sections will present the implications of these findings for professionals, patients and families, and theory and future research in this field.

### **Implications for Healthcare Institutions**

The findings of my research provide several insights that inform the policy and practices of healthcare institutions. As in previous sections of this chapter, participants in my research shared, explicitly and implicitly, their understanding of conscience as a faculty that supports the relationships that are necessary for the provision of holistic care. Further, from the viewpoints of the palliative care team, conscience does not function properly in isolation, but rather conscience is fostered by collaborative teams in an environment that promotes open and honest communication. If one is to learn from the effectiveness of the palliative care team example then

efforts to promote the tools outlined in this dissertation need be strengthened. For example, some members of the interpretive panels consulted in my research suggested that team collaboration could be ameliorated through the adoption of microsystems and a greater emphasis on communication skills development throughout the training of healthcare professionals. Such changes present challenges, but they could create a culture that is capable of achieving the benefits of engaged consciences while ensuring respect for the values of healthcare professionals and those they serve.

Institutional support for the engagement of professionals' consciences through clear communication and a collaborative environment are the first steps towards creating Goodpaster's culture of ethical awareness. However, maintaining this culture requires buy-in not only from the healthcare professionals responsible for direct patient care, but also from management. In my research, many palliative care team members emphasized that the leadership of their physicians heavily influenced the team's culture. The team approach to holistic care was further promoted by nurse coordinators and unanimously endorsed by the team members who were interviewed. This is in keeping with Goodpaster's emphasis on the indispensable role played by managers, as he explained that persons in such leadership roles serve as a bridge between organizational values and the values of employees. I posit that, following the example of the palliative care team's leadership, managers in healthcare institutions could develop and maintain a culture of ethical awareness by clearly communicating the values of their health regions, hospitals, long-term care homes, and professional regulatory bodies (to name a few institutions), while communicating their team members' values to senior leadership. To accomplish this latter function, managers need to provide those under their leadership with the space they need to develop their consciences and openly communicate their moral judgments. Turning again to

Hirschman's emphasis on voice, managers who successfully perform this role may benefit the healthcare system by creating a culture in which members can give voice to their conscience concerns. This is no easy task for managers, and, as suggested by some members of the interpretive panel, these healthcare leaders will likely require institutional supports (e.g., training) rather than restrictive policies.

In concert with many interpretive panel members, I suggest that a culture of ethical awareness is most likely to be achieved through policies that are supportive of a cultural shift that emphasizes the use of the tools outlined in this dissertation, and they need not be restrictive. For example, several members of the palliative care team shared the difficulties of prescribing pain medication to patients who had a history of drug abuse. In their descriptions of such situations, participants expressed their gratitude for team members who helped them to see their patient holistically. If faced with a similar situation, it may be that healthcare professionals in other disciplines would also benefit from the collaboration of a team with which they can form moral judgments regarding the care of patients with drug addictions. Conversely, given the complexity of such situations, a restrictive policy is not likely to capture the intricacies of a patient's psychosocial environment or improve patient care. The palliative care team's positive use of the tools detailed in this dissertation suggests that healthcare delivery may be improved if healthcare institutions, including educational colleges, are encouraged to use the means at their disposal to promote open communication and interdisciplinary teams that are oriented towards the provision of holistic care. In my assessment, this will require, among other things, that institutions trust their members, modeling the trust that is necessary for positive healthcare professional-patient relationships and the creation of a culture of ethical awareness that engages the consciences of members at every level of the institutional hierarchy.

## **Implications for Healthcare Professionals**

The findings of this dissertation indicate that, for palliative care team members, conscience is an indispensable tool for personal, professional, and collective decision-making; however it is also necessary to note that conscience's proper use demands several things from healthcare professionals. First, in tandem with Schon's (1984) description of the reflective practitioner, participants in my research emphasized the importance of self-awareness and reflection during ethically challenging situations. Although members of the interpretive panels did not agree on whether the capacity for reflection is a natural ability or an acquired skill that requires cultivation, many participants throughout my research noted instances when their self-awareness and capacity for reflection were sharpened by collaboration and honesty among members of an interdisciplinary team, which is in keeping with Bebeau's (1995) emphasis on reflection as a skill that can be developed by science professionals. Several members of the interpretive panels and the palliative care team described reflection as a tool that helps healthcare professionals to identify their own needs, opinions, beliefs and values as well as those of the people around them. As outlined in Figure 7.1, I have interpreted moral reflection as providing healthcare professionals with the insights they need to make moral judgments. Given the important role of self-awareness and reflection, I posit that the care provided by healthcare professionals is likely to improve if these professionals develop their capacity for self-reflection throughout their education and professional development, particularly if they are supported by the institutions in which they serve.

Second, the findings of my research indicate that a healthcare professional's integrity benefits her patients, coworkers, and the institutions in which she serves. Several members of the palliative care team stated that they would not be able to perform their job without their

conscience, while some members of the interpretive panel focused on the negative impact that moral distress can cause in healthcare professionals who cannot follow through on the judgments of conscience. In my assessment, it seems appropriate, therefore, to encourage healthcare professionals to assume responsibility for safeguarding their integrity and minimizing their exposure to moral distress whenever possible. Additionally, as one member of the first interpretive panel commented, it seems that healthcare professionals could also benefit from learning how to manage their moral distress when it does occur. As with self-reflection, I observed in the stories shared by the palliative care team that integrity also benefits from open communication and collaborative teams, and requires support from all levels of the healthcare system, which I extend to include professional organizations and educational institutions. For example, collaborative teamwork requires first, that healthcare professionals receive training to learn how to collaborate as part of an interdisciplinary team, and second, that they are supported by institutional structures that promote team cohesion, such as being given enough time for regular team meetings. Additionally, the care provided by healthcare professionals may improve if the healthcare professionals themselves take responsibility for developing these tools in the discipline in which they serve. This is in keeping with Wilson's (1991) focus on autonomy and mission in successful organizations, and I suggest that providing healthcare professionals with the freedom to develop and maintain these tools has the potential to support a sense of mission among team members that could help them to remain conscientiously engaged in their work.

### **Implications for Patients and Families**

Although the design of my research did not include interviews with patients and families, this dissertation provides some implications for users of the healthcare system. Research on moral distress suggests that healthcare professionals perform better if they are in a supportive

culture (Burston and Tuckett 2012), which all of the palliative care team members in my research stated was present in palliative care services. Given the high degree of patient and family involvement in patient-centred holistic care, I propose that patients and families who engage their healthcare professionals in authentic relationships and make an effort to clearly communicate with them benefit by improving the chances that the care team will be able to find a positive resolution to conscientious disagreements, or avoid such disagreements altogether. For example, in the stories shared by participants in my research, patients who were willing to share their experiences beyond their physical symptoms at the end of life (e.g., those who shared their desire to return home) and establish trusting relationships with the palliative care team tended to receive better care because their honesty enabled the team to provide psychosocial support. Although there is a power imbalance that cannot be removed between healthcare professionals and those they serve (Downie and Llewellyn 2008), my research indicates that these imbalances can be mitigated through the deliberative processes mentioned throughout this dissertation, particularly through the healthcare professionals' self- and situational-awareness and commitment to patient-centred holistic care. This has the potential to improve the healthcare professional-patient relationship and to help all concerned avoid the costly and adversarial process of litigation as a resolution to conscientious disagreements. Further research is needed to investigate patient satisfaction with healthcare professionals who engage their consciences, and to examine the role of patients and families as members of the healthcare team.

### **Implications for Theory and Future Research**

The implications of this dissertation stretch beyond the context of healthcare into broader areas of theory and topics of future research. First, the findings of my research carry implications for theory relating to power structures in relationships. This dissertation has viewed power



through the lens suggested by Lukes (2005), which helped to categorize Downie and Llewellyn's (2008) description of forces that influence relational autonomy. However, the relationships found in healthcare can also be understood through different power frameworks, such as French and Raven's bases of power. In this framework, there are six bases of power that categorize the potential to influence "a change in belief, attitude, or behaviour of a person" (Raven 2008, 1). Given the disparity in knowledge and skill between healthcare professionals and patients, their relationships are predominantly based in expert power. This conclusion is supported by this dissertation, as participants tended to describe situations in which their role as experts with superior knowledge (e.g., of pain management or the patient placement system) allowed them to influence their patients. However, participants were aware of this degree of influence, and made an effort to be honest about their goals and to discern which information about their motivations was valuable for those in their care. For example, in cases involving persons with drug addictions, participants described that they clearly stated the goals of palliative care but generally elected not to disclose any personal reservations about treating persons with drug addictions they may have had. Some participants explained this decision, saying that they felt they could manage these reservations without affecting patient care, while others stated that they were concerned that articulating these reservations would damage their relationship with their patient. My own observations suggest that participants used their consciences to help them navigate whether information about their own deliberative processes would best serve patients and their families; however further research is needed to establish what impact this had on patients and families from their perspectives.

Second, although my research was conducted in the unique context of palliative care, it has the potential to inform theory and research pertaining to the role of conscience outside this

context. As noted by one interpretive panel member, the provision of holistic care is different outside the palliative care team, and the themes that emerged during my research may not apply directly to other contexts. Although this caution must be noted, I posit that there remains a strong possibility that the deliberative processes of palliative care could prove valuable in other healthcare contexts as well as in contexts outside of healthcare, such as the public sector. As Goodpaster observed, organizations rely on the consciences of individual members to form a culture of ethical awareness that prevents unethical actions. This observation is supported by the findings of my research as well as by the literature on public sector ethics. For example, in their analysis of the sponsorship scandal, Atkinson and Fulton (2013) argued that, “the real source of the policy failure was an organizational subculture that rationalized everyone’s behavior by claiming that in this case the rules did not apply.” This conclusion indicates that a culture of ethical awareness did not exist in the areas of the public service affected by the sponsorship scandal, and that the public servants themselves did not have the tools they required to engage in ethical behaviour. The findings of this dissertation suggest that other areas of healthcare and the public service may benefit from the tools employed by the palliative care team to create and maintain a culture of ethical awareness; however further research is needed to determine whether or not the palliative care team’s deliberative processes could be useful in such different contexts.

## **Conclusions**

As one of the few institutions that are shared by all Canadians, our healthcare system has become a forum for value discussions that engage some of our most deeply held beliefs concerning the way we live and the way we die (Somerville 2004). These discussions take place in an intricate web of relationships between healthcare professionals, patients and families, and can sometimes lead to conscientious disagreements. These disagreements are unavoidable, and

although they can escalate into conflicts, they can also be addressed in a manner that leads all involved to a positive resolution that respects the autonomy of patients and healthcare professionals.

Having observed that palliative care teams are able to achieve positive outcomes for patients and families despite regular exposure to the end-of-life decisions from which conscientious disagreements are likely to arise, I have employed a narrative methodology to investigate the deliberative processes of the Saskatoon Health Region's palliative care team. The findings of my research indicate that conscience plays a key role in helping healthcare professionals to find a positive resolution in situations where they may disagree with the ethical judgments of patients and families. At these times, conscience both supports and is supported by the relationships formed between healthcare professionals and those they serve, as well as by an environment that promotes holistic care, collaborative teamwork, and clear communication.

Although some have called for healthcare professionals to leave their consciences out of their workplace, this dissertation supports the conclusion that conscience is required to maintain a culture of ethical awareness within our healthcare system. Such a culture is necessary to ensure that our institutions continue to be grounded in ethical decision-making, which benefits individual members as well as the organization as a whole. In the context of healthcare, an organizational culture that sees conscience as an asset to be supported rather than a liability to be managed is likely to witness a decrease in instances of moral distress among healthcare professionals. Further, institutions that adopt policies that promote conscience using the tools mentioned throughout this dissertation may have the added benefit of avoiding protracted court cases as a means to resolve conscientious disagreements. Such policies have the potential to reinforce trusting relationships that are founded on honesty among members of the healthcare

team and those they serve, enabling them to reach positive resolutions in ethically challenging situations.

The healthcare professional-patient relationship is the backbone of the Canadian healthcare system. This relationship is founded on trust, and in times of stress, particularly during ethically challenging moments at the end of life, it needs to be supported by an organizational culture that respects the needs, opinions, beliefs and values of healthcare professionals, patients and families. This dissertation has analyzed the role of conscience in these relationships and provided evidence that healthcare professionals' consciences are indispensable to their deliberative processes both as individuals and as team members. This evidence indicates that policies concerning conscience issues will be most effective if they are created with the goal of supporting conscience in the web of relationships found throughout our healthcare institutions. The ethical flourishing of the Canadian healthcare system is rooted in the consciences of its individual members, supported by the healthcare professional-patient relationships, and reaches its full maturity in patient-centred, holistic care that is tended by collaborative teams and clear communication.

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## **Appendices**

**Appendix A:**

**Letters of Initial Contact / Consent Forms / Transcript Release Form**

*Letter of Initial Contact*  
*Interview and Focus Group*

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**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

Dear \_\_\_\_\_,

I am conducting a PhD research project through the University of Saskatchewan regarding decision making in palliative care, and the manager of palliative care encouraged me to contact you as a potential participant who could share her expertise in palliative care. Participation in this research is voluntary and will have no bearing on your employment or professional standings. This study should take no more than three hours of your time. If you choose to be involved, you would be invited to participate in both a personal interview and a focus group with other members of the palliative care team. Each of these sessions will last one hour, and you may also be asked to provide a brief follow up interview by telephone, e-mail, or in person.

Your interview would be conducted at a location of your choosing to provide you with an appropriate space to reflect on your experiences and avoid distraction. The interview will be recorded and transcribed, and, following your release of the transcript for use, it will be included in the data collected in this research. You will be free to withdraw from this study at any point before you release the interview transcript. You will also be invited to participate in a focus group that will convene at a Saskatoon Health Region (SHR) facility. The transcripts of your interview and the focus group session will be analyzed along with interviews from other palliative care team members. This analysis will be given to a focus group comprised of members of the SHR's leadership, who will comment on whether the decision making processes used in palliative care may inform policies in other areas of the healthcare system.

The purpose of this research is to articulate what decision making processes, if any, lead to positive outcomes in situations where palliative care team members find themselves in disagreement with a patient or his or her family over a treatment plan. Once articulated, I will address whether these conditions may inform the development of policies to mediate disagreements in other areas of the healthcare system.

This study has received approval from the Behavioural Research Ethics Office of the University of Saskatchewan. Your answers may be quoted in future publications and presentations, but your name and all other identifying information will not be linked to these quotes.

If you have any questions, please do not hesitate to contact one of the researchers at the e-mail addresses listed below. We would appreciate receiving your response by \_\_\_\_\_.

Sincerely,  
Mary Deutscher  
PhD Candidate  
mkd497@mail.usask.ca

Dr. Keith Walker  
Professor  
keith.walker@usask.ca

*Letter of Initial Contact  
Interpretive Panel*

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**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

Dear \_\_\_\_\_,

I am conducting a PhD research project through the University of Saskatchewan regarding decision making in palliative care, and would like to request an hour of your time to share the expertise you have developed as a leader in the Saskatoon Health Region (SHR). Participation in this research is voluntary and will have no bearing on your employment or professional standings. If you choose to be involved, you will be asked to partake in a one-hour focus group in a SHR facility.

Over the past five months, I have conducted a series of interviews and a focus group with members of the SHR's palliative care team. The purpose of these sessions was to articulate what decision making processes, if any, lead to positive outcomes in situations where palliative care team members find themselves in disagreement with a patient or his or her family over a treatment plan.

The transcripts of these sessions were analyzed, and will now be presented to two interpretive panels (a type of focus group) that will each meet for one hour to comment on whether these findings may be used to inform policies in other areas of the healthcare system. Your role in this study would be to sit on an interpretive panel.

This study has received approval from the Behavioural Research Ethics Office of the University of Saskatchewan and the Saskatoon Health Region. The panel's discussion may be quoted in future publications and presentations, but your name and all other identifying information will not be linked to your quotes.

If you have any questions, please do not hesitate to contact one of the researchers at the e-mail addresses listed below. We would appreciate receiving your response by \_\_\_\_\_.

Sincerely,

Mary Deutscher  
PhD Candidate  
mkd497@mail.usask.ca

Dr. Keith Walker  
Professor  
keith.walker@usask.ca

*Participant Consent Form  
Interview*

---

**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

**Researcher(s):** Mary Deutscher, PhD candidate, Johnson-Shoyama Graduate School of Public Policy, College of Graduate Studies and Research, University of Saskatchewan, (306) 717-6167, mkd497@mail.usask.ca

**Supervisor:** Dr. Keith Walker, Johnson-Shoyama Graduate School of Public Policy, (306) 966-8465, keith.walker@usask.ca

**Purpose(s) and Objective(s) of the Research:**

- The purpose of this research is to articulate what decision making processes, if any, lead to positive outcomes in situations where palliative care team members find themselves in disagreement with a patient or his or her family over a treatment plan. Once articulated, the researcher will address whether these conditions may inform the development of policies to mediate disagreements in other areas of the healthcare system.

**Procedures:**

- Over a period of six to eight weeks, the researcher will conduct an hour-long interview with each of up to ten participants. These sessions will be conducted at a location of the participant's choosing to provide participants with an appropriate space to reflect on their experiences and avoid distraction. These sessions will be recorded and transcribed, and will be included in the data collection section of this project following release for use by the interviewee.
- Participants will also be invited to participate in a one-hour focus group in a Saskatoon Health Region facility that will be conducted after the completion of all participants' interviews.
- Participants may be contacted by phone, e-mail, or in person for a follow up interview.
- The transcripts of the interviews and the focus group will be analyzed. This analysis will be given to an interpretive panel (a type of focus group) comprised of health region leadership who will comment on whether the deliberative processes used in palliative care may inform policies in other areas of the healthcare system.
- Your role in this study would be to serve as an interviewee and focus group member.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:**

- There are no known or anticipated risks to you by participating in this research.

### **Potential Benefits:**

- The findings of this study could inform the creation of policy that would prevent the financial and emotional costs of protracted court cases and enhance the relationships between healthcare professionals and patients, thereby strengthening the healthcare system.

### **Confidentiality:**

- The data from this research project will be published and presented at conferences; however, your identity will be kept confidential. Although the researcher will report direct quotations from the interview, you will be given a pseudonym, and all identifying information will be removed from our report
- Because the participants for this research project have been selected from a small group of people, all of whom are known to each other, **it is possible that you may be identifiable to other people on the basis of what you have said.** In particular, participants may be known to members of the interpretive panel that will comment on the data gathered from the interviews.
- After your interview, and prior to the data being included in the final report, you will be given the opportunity to review the transcript of your interview, and to add, alter, or delete information from the transcripts as you see fit.
- Your interview will be recorded as an audio file. You may request that the recording device be turned off at any time.

### **Storage of Data**

- All electronic data (including audio files) will be stored on a password protected USB drive and on the PAWS Cabinet secure network.
- Paper documents will be stored in a locked filing cabinet in the researcher's office.
- Consent forms will be stored separately from the data.
- When data is no longer required, electronic data will be permanently deleted and paper documents will be shredded.

### **Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions with which you are comfortable. Before you have signed the transcript release form, you may withdraw from the research project for any reason, without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your position [e.g. employment, class standing, access to services] or how you will be treated.
- Should you wish to withdraw before you have signed the transcript release form, any data collected about you will be destroyed.
- Your right to withdraw your interview data from the study will apply until you sign the transcript release form. After this time, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Follow up:**

- A plain language report will be made available to all participants upon completion of the project.

**Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**Consent**

Your signature below indicates that you have read and understand the description provided.

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***



*Participant Consent Form*  
*Focus Group*

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**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

**Researcher(s):** Mary Deutscher, PhD candidate, Johnson-Shoyama Graduate School of Public Policy, College of Graduate Studies and Research, University of Saskatchewan, (306) 717-6167, mkd497@mail.usask.ca

**Supervisor:** Dr. Keith Walker, Johnson-Shoyama Graduate School of Public Policy, (306) 966-8465, keith.walker@usask.ca

**Purpose(s) and Objective(s) of the Research:**

- The purpose of this research is to articulate what decision making processes, if any, lead to positive outcomes in situations where palliative care team members find themselves in disagreement with a patient or his or her family over a treatment plan. Once articulated, the researcher will address whether these conditions may inform the development of policies to mediate disagreements in other areas of the healthcare system.

**Procedures:**

- Over the past two months, the researcher has conducted a series of interviews with members of the Saskatoon Health Region's palliative care team. The purpose of these interviews was to articulate what conditions, if any, lead to positive outcomes in situations where palliative care team members and those they serve find themselves in disagreement over a patient's treatment plan.
- Participants who completed an interview are now invited to join a one-hour focus group that will take place in a Saskatoon Health Region facility.
- Participants may be contacted by phone, e-mail, or in person for a follow up interview.
- The transcripts of the interviews and the focus group will be analyzed. This analysis will be given to an interpretive panel (a type of focus group) comprised of health region leadership who will comment on whether the deliberative processes used in palliative care may inform policies in other areas of the healthcare system.
- You have already participated as an interviewee in this study and are now invited to participate as a focus group member.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

### **Potential Risks:**

- There are no known or anticipated risks to you by participating in this research.

### **Potential Benefits:**

- The findings of this study could inform the creation of policy that would prevent the financial and emotional costs of protracted court cases and enhance the relationships between healthcare professionals and patients, thereby strengthening the healthcare system.

### **Confidentiality:**

- The data from this research project will be published and presented at conferences; however, your identity will be kept confidential. Although the researcher will report direct quotations from the focus group, you will be given a pseudonym, and all identifying information will be removed from our report
- The researcher will undertake to safeguard the confidentiality of the focus group discussion, but cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others may not respect your confidentiality.
- Because the participants for this research project have been selected from a small group of people, all of whom are known to each other, **it is possible that you may be identifiable to other people on the basis of what you have said.** In particular, participants may be known to members of the interpretive panel that will comment on the data gathered from the interviews and focus group.
- The focus group's discussion will be recorded as an audio file and transcribed for use by the researcher.

### **Storage of Data**

- All electronic data (including audio files) will be stored on a password protected USB drive and on the PAWS Cabinet secure network.
- Paper documents will be stored in a locked filing cabinet in the researcher's office.
- Consent forms will be stored separately from the data.
- When data is no longer required, electronic data will be permanently deleted and paper documents will be shredded.

### **Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions with which you are comfortable.
- Whether you choose to participate or not will have no effect on your position [e.g. employment, class standing, access to services] or how you will be treated.
- Full withdrawal is only possible before the focus group's session begins. Should you choose to withdraw after this time, you may leave the session before it is concluded, but it will not be possible to withdraw your data.
- Once the session has begun, the recording device will not be turned off; however, participants may choose to leave the room.

**Follow up:**

- A plain language report will be made available to all participants upon completion of the project.

**Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**Consent**

Your signature below indicates that you have read and understand the description provided.

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher***

*Participant Consent Form  
Interpretive Panel*

---

**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

**Researcher(s):** Mary Deutscher, PhD candidate, Johnson-Shoyama Graduate School of Public Policy, College of Graduate Studies and Research, University of Saskatchewan, (306) 717-6167, mkd497@mail.usask.ca

**Supervisor:** Dr. Keith Walker, Johnson-Shoyama Graduate School of Public Policy, (306) 966-8465, keith.walker@usask.ca

**Purpose(s) and Objective(s) of the Research:**

- The purpose of this research is to articulate what decision making processes, if any, lead to positive outcomes in situations where palliative care team members find themselves in disagreement with a patient or his or her family over a treatment plan. Once articulated, the researcher will address whether these conditions may inform the development of policies to mediate disagreements in other areas of the healthcare system.

**Procedures:**

- Over the past several months, the researcher has conducted a series of interviews and a focus group with members of the Saskatoon Health Region's palliative care team. The purpose of these sessions was to articulate what conditions, if any, lead to positive outcomes in situations where palliative care team members and those they serve find themselves in disagreement over a patient's treatment plan.
- The transcripts of these interviews were analyzed, and will now be presented to two interpretive panels (a type of focus group) that will each meet for one hour to comment on whether these findings may inform policies in other areas of the healthcare system.
- Your role in this study would be to sit on an interpretive panel. The panel's session will be conducted at a health region facility, and will last no more than one hour.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:**

- There are no known or anticipated risks to you by participating in this research.

**Potential Benefits:**

- The findings of this study could inform the creation of policy that would prevent the financial and emotional costs of protracted court cases and enhance the relationships between healthcare professionals and patients, thereby strengthening the healthcare system.

### **Confidentiality:**

- The researcher will undertake to safeguard the confidentiality of the discussion, but cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others may not respect your confidentiality.
- Because the participants for this research project have been selected from a small group of people, all of whom are known to each other, **it is possible that you may be identifiable to other people on the basis of what you have said.**
- The interpretive panel's discussion will be recorded as an audio file and transcribed for use by the researcher.

### **Storage of Data**

- All electronic data (including audio files) will be stored on a password protected USB drive and on the PAWS Cabinet secure network.
- Paper documents will be stored in a locked filing cabinet in the researcher's office.
- Consent forms will be stored separately from the data.
- When data is no longer required, electronic data will be permanently deleted and paper documents will be shredded.

### **Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions that you are comfortable with. Before the panel's session is conducted, you may withdraw from the research project for any reason, without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your position [e.g. employment, class standing, access to services] or how you will be treated.
- Should you wish to withdraw before the session is conducted, any data collected about you will be destroyed.
- Full withdrawal is only possible before the interpretive panel's session begins. Should you choose to withdraw after this time, you may leave the session before it is concluded, but it will not be possible to withdraw your data.
- Once the session has begun, the recording device will not be turned off; however, participants may choose to leave the room.

### **Follow up:**

- A plain language report will be made available to all participants upon completion of the project.

### **Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;

- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

### **Consent**

Your signature below indicates that you have read and understand the description provided;

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

*Transcript Release Form*

---

**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

I, \_\_\_\_\_, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Mary Deutscher. I hereby authorize the release of this transcript to Mary Deutscher to be used in the manner described in the Consent Form. I have received a copy of this Transcript Release Form for my own records.

\_\_\_\_\_  
*Name of Participant*                      *Signature*                      *Date*

\_\_\_\_\_  
*Researcher's Signature*                      *Date*

***A copy of this release will be left with you, and a copy will be taken by the researcher.***

## **Appendix B:**

### **Questions for Semi-Structured Interviews, Focus Group and Interpretive Panel**



## **Questions for Semi-Structured Interviews with Correlating Research Question Marked**

Question	1. What are the experiences of team members who have been directly involved in decisions that engage their consciences within the culture of palliative care?	2. How do palliative care providers describe the deliberative processes used at personal, professional and team levels, regarding end-of-life care?	3. What part of the deliberative processes described by palliative care team members contributes to the successful mediation of conscientious disagreements between healthcare professionals and patients, as perceived by the healthcare professionals?	4. What aspects of palliative care providers' deliberative processes provide insights that inform the development of policy and/or reflections on the practices of professionals in other areas of the healthcare system?
1. Please describe the kind of work you do and the services you provide.				
2. Would you share the story of how you became a member of your profession, and how you've developed your skills over the years?				
3. Is there a story connected to your joining the palliative care team?				
4. When you think about what drives your service and the efforts you make to be a part of the palliative care team – what explains your motivation and your decision to stay on with this work?				
5. Is there an example that				

you can think of that expresses the underlying philosophy and values of palliative care and the culture that your team has developed?				
6. Have you ever been involved with a patient who did not initially understand the purpose, values, and philosophy of palliative care? How was this explained to them? How would you describe their response?	X			
7. Would you share a typical experience around the decision-making that goes into making a patient's care plan? Could you give an example? a. How did the team approach this decision? b. What was your role when the care plan was being developed? c. Do you	X	X		

<p>feel the patient and/or the family was involved in forming the care plan?</p> <p>d. How was the care plan presented to the patient/family?</p>				
<p>8. During your time with palliative care, have you ever been involved in a situation where a difficult moral decision had to be made?</p> <p>a. How did you personally engage the moral issue?</p> <p>b. How did the team approach this decision?</p> <p>c. What was your role as part of the team?</p> <p>d. Do you feel the patient and/or the family was involved in making the decision?</p>	X	X		

<p>9. Have you been involved in a case where the patient and/or his or her family did not agree with the palliative care team's care plan? Would you share this story?</p> <p>a. How was this situation handled by the care team?</p> <p>b. How were you involved in the decisions made by the care team?</p> <p>c. How did you personally approach this disagreement?</p> <p>d. Did the disagreement affect the way you interacted with the patient and/or the family?</p>	X	X		
<p>10. "Moral distress" is defined by Andrew Jameton as something that arises when "one knows</p>	X			

the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.” Have you ever been involved with a patient and felt moral distress? Would you describe the situation?				
11. What do you think are the key tools used by palliative care team members when they are faced with challenging or ethical decisions?		X		
12. In your experience how does conscience fit into your work and the work of others?		X		
13. What do you think are the most important tools used by the palliative care team to make decisions regarding patient care?		X	X	X
14. When you think about the decision making processes used in palliative care, do you think any of the tools or processes of			X	X

palliative care could be used in other areas of healthcare?				
15. Would you share a story that highlights the strengths of palliative care? What stories or events or decisions come to mind when you think of palliative care at its best?				

## **Questions and Handouts for Semi-Structured Palliative Care Team Focus Group**

*Present focus group with a hierarchy chart of their team structure for them to review:*

1. Do I have the opportunities for formal communication correct?
  - Nursing handoff in the morning – recorded? In person?
  - Morning handover rounds: physicians, Pall Care Unit Nurse Coordinator, social work, music therapy
  - Morning phone call (5-10 minutes) with other hospital RN Coordinators and community palliative homecare coordinator
  - Bedside rounds
  - Afternoon Team Huddle (afternoon handoff?)
  - Wednesday Rounds (includes physio, etc.)
  - Frequent communication throughout the day as needed

*Present concept map from initial stages of research and explain importance of learning about palliative care's decision-making tools*

2. In our interviews, team members offered different descriptions of conscience, but for the most part there were three ways of thinking about conscience:

1. A personal voice that tells you right from wrong and stops you from sleeping at night if you don't listen to it. (Jiminy Cricket)
  2. A personal motivator that keeps you working hard (Conscientiousness)
  3. A navigation tool that helps you get through complex and challenging situations. (Compass)
- Is your conscience only one of these things?
  - Is it all of these things?
  - How do they interact?
  - Do certain members of your team hold different parts of conscience more than others?
  - I've heard people say that healthcare professionals should, "leave their conscience at home?"
    - Is it possible for you to "leave your conscience at home"?
    - How would you personally be affected if you acted against your conscience?
    - Would your work be affected if you "left your conscience at home"?
    - Would your team be affected if you "left your conscience at home"?
    - Would your patients and their families be affected if you "left your conscience at home"?

3. Can you think of a time when a palliative care team member had to work against their conscience? e.g., moving someone into long-term care

- Could you describe what, if any, moral distress this caused?
- Do you feel that it affected the quality of the person's work?
- Did it affect their work in other areas, i.e., did it have a cumulative effect?
- Do you feel that it affected the person's relationship with the patients or families?

- How did the team approach the situation?

4. In our interviews, many staff members contrasted Palliative Care with Surgery. When you think about the relationships between staff and patients/families, how do these two areas of medicine differ? Could you think of a story that exemplifies the relationships found in palliative care?

5. I've noticed in the stories that I heard in our interviews together that having a positive relationship with patients and families makes difficult decisions easier to manage. Does this observation seem accurate?

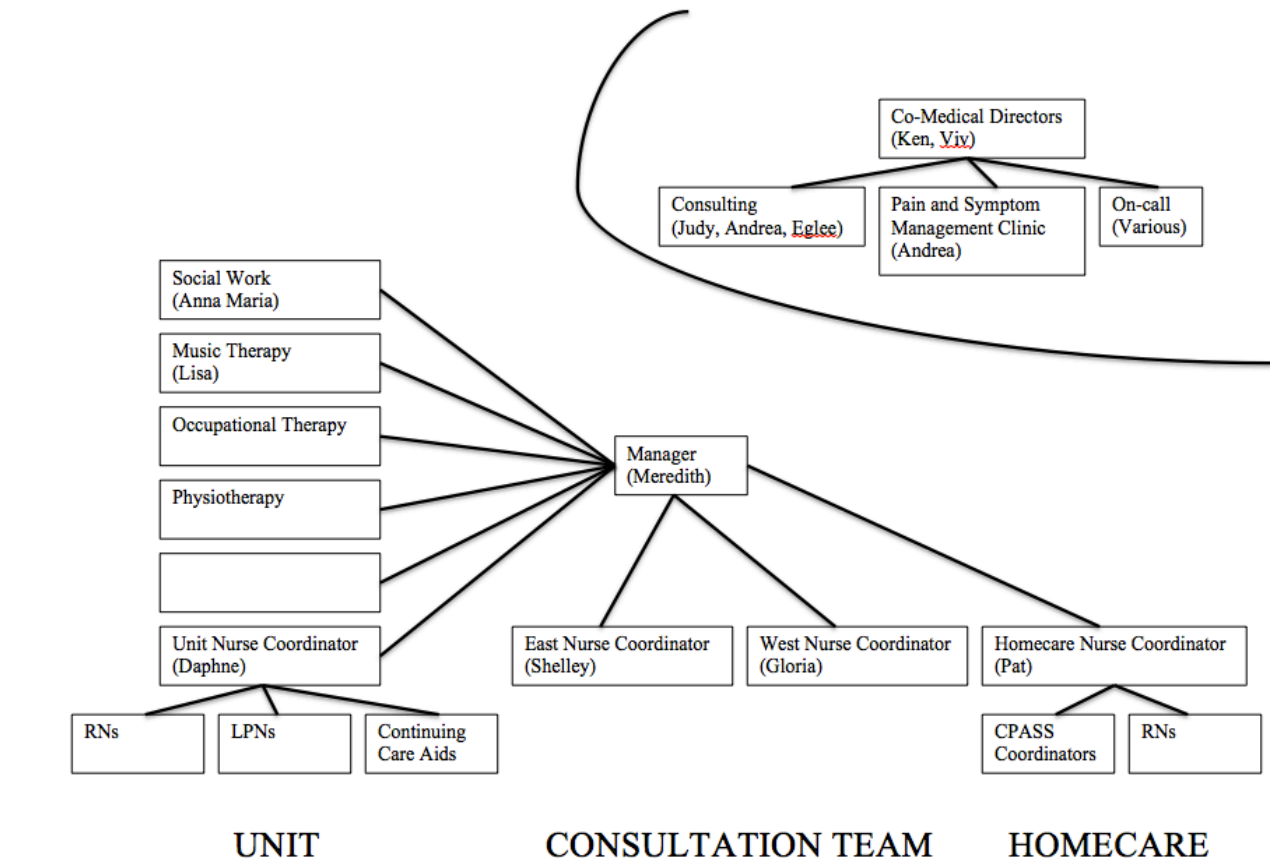
6. Building on this: Can you think of a time when the team had difficulty establishing a rapport with a patient?

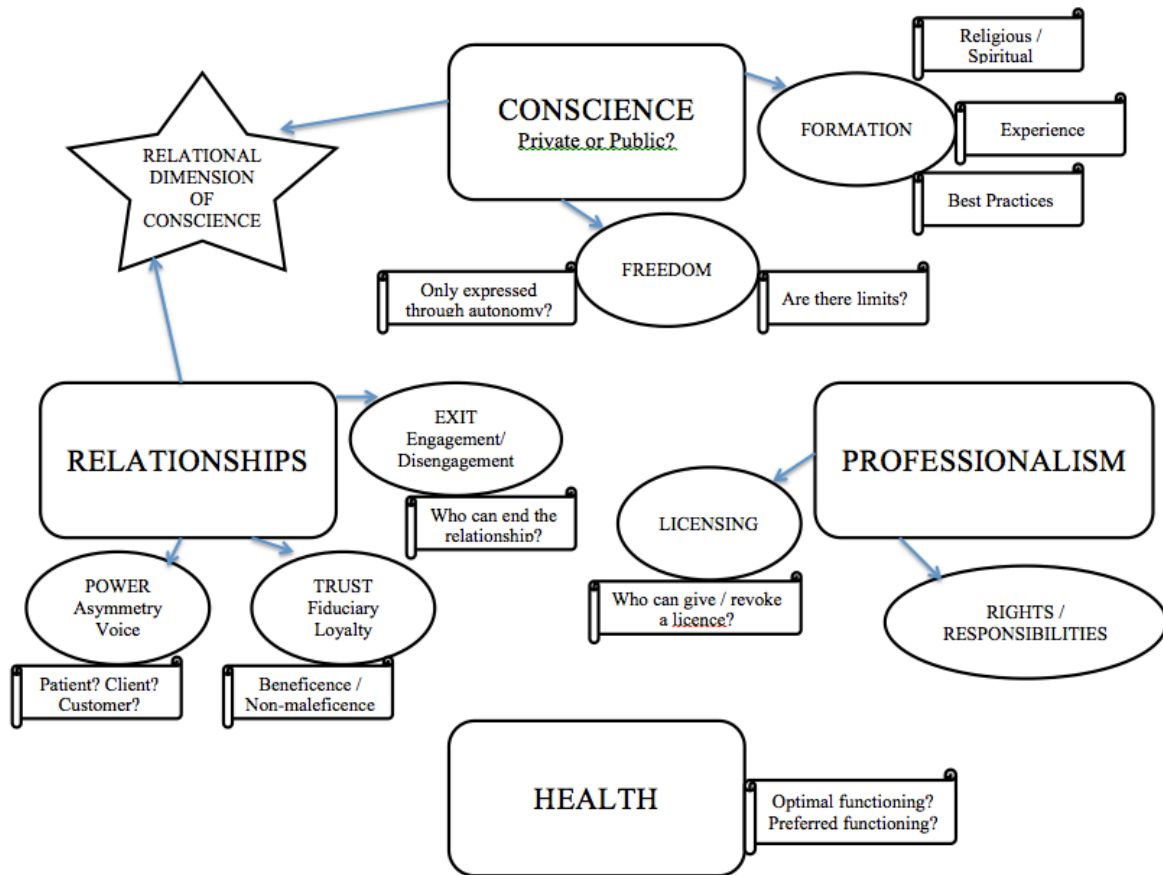
- How did it affect your work?
- Were you able to gain their trust?

7. In our interviews, many team members described times that they could not fulfill a patient/family's request. e.g., allowing them to misuse pain medication, allowing them on the unit without a DNR, allowing them to disregard isolation protocols

- How did the patient/family express their disagreement?
- Do you think the patient thought they were treated with respect?
- One author that I've read worries that when patients are told that they cannot have a treatment, it injures them, making it difficult for them to speak up again. Do you feel the patient was still able to make and express decisions within the options you gave him or her?
- Were you able to maintain the patient's trust in this situation?







## **Questions and Handouts for Semi-Structured Interpretive Panel 1**

*Explain motivation for project*

**Research Question:** What aspects of palliative care providers' deliberative processes provide insights such as informs the development of policy and/or reflections on the practices of providers in other areas of the healthcare system?

-Or, do any of the tools used in palliative care provide insights that could be useful in the creation of policies, etc. in other areas of the health region?

### **A. Findings: Decision-making tools**

*Embodied Example: Read Quotation 1*

#### **a. Clear communication:**

- frequent communication between team members
- frequent communication with patients
- skilled communicators
  - in a position where they can be very clear on the goals of care
- make time and space for discussions
- “being able to listen and communicate with [our] patient is very import to us because otherwise we don't find out what's important to that patient and sometimes we can facilitate - with the other team members - a whole care that takes in that whole person - or that idea of holistic suffering.”

#### **b. Collaborative team approach:**

- trust each others decisions
- trust each others' ability to connect with a patient, whenever that moment arises
- strong leadership from physicians, who welcome input from other team members
- consult with each other regarding difficult situations
- intentional team building
- “if we don't feel in relationship with the place we work, how can we provide relationship to patients and families?”

#### **c. Holistic care:**

- patient and family centered
- see the patient in his or her own story as a person with their own set of relationships
  - “none of us really aspires to be ‘the pancreas in [room] 574’”
- process oriented, not task oriented, journeying with patients
- can catch problems earlier because patients will communicate better when they feel team members care about them as people, not as diseases
- team members bring their whole selves to their work, including their conscience

#### **d. Real relationships**

- relationships are necessary to establish trust and open up communication
- allows deeper healing on a psychosocial level

- need to bring your whole self to a relationship, not just a professional mask
  - difficult balance between being professional and being authentic
- relationship building requires physical space, time, and psychosocial space

#### **e. Engaged consciences:**

- the team understood conscience to have three dimensions:
  1. arbiter of right and wrong
  2. instilling conscientiousness
  3. navigation tool
- if they are not allowed to express their consciences in their relationships, health care workers become like robots who cannot build real relationships
- caring, compassionate people need their consciences and cannot block off certain parts of it and keep others
- “I think conscience drives you to be the best you can be.”

1. **To begin with, what are your initial reactions to these results? Are you surprised that the palliative care team relies on their team approach, holistic care, and strong communication skills?**
2. **Have you had any experiences with palliative care where you have seen these decision-making tools at work?**
3. **Have you had any experiences in other areas of the hospital where you have seen these tools employed by other teams?**
4. **In your experience developing policies for the health region, do you feel that fostering healthy relationships is a focus of your discussions?**
5. **The palliative care team members viewed their own consciences and the consciences of their team members as an asset in their work. In your experience, are the consciences of health care professionals viewed as an asset to the health region?**

#### **B. Future policy**

Read quotation 2

**6. Could the tools used on palliative care provide insight into the practices of healthcare providers in other areas of the healthcare system?**

**7. Could the tools used on palliative care inform the development of future policies?**

**-For example, the health region will likely be crafting new policies around end-of-life care in the near future. How might these policies support holistic care/communication/teamwork?**

#### **C. Practical possibilities**

- have a picture of the patient from when they were healthy next to ever bed
- how to say ‘no’: “That’s the thing - it’s not just a ‘no.’ It’s generally a conversation - it opens the door to a conversation.”
- education on communication skills? – e.g., sit down with patients, frame questions in an accessible way

- assign support staff to specific areas and make them feel part of a team
- encourage creativity
- would electronic records help ensure that these discussions don't have to be rushed over and over again?

**F. Other**

**8. Does the health region have any statistics for patient/family satisfaction in palliative care?**

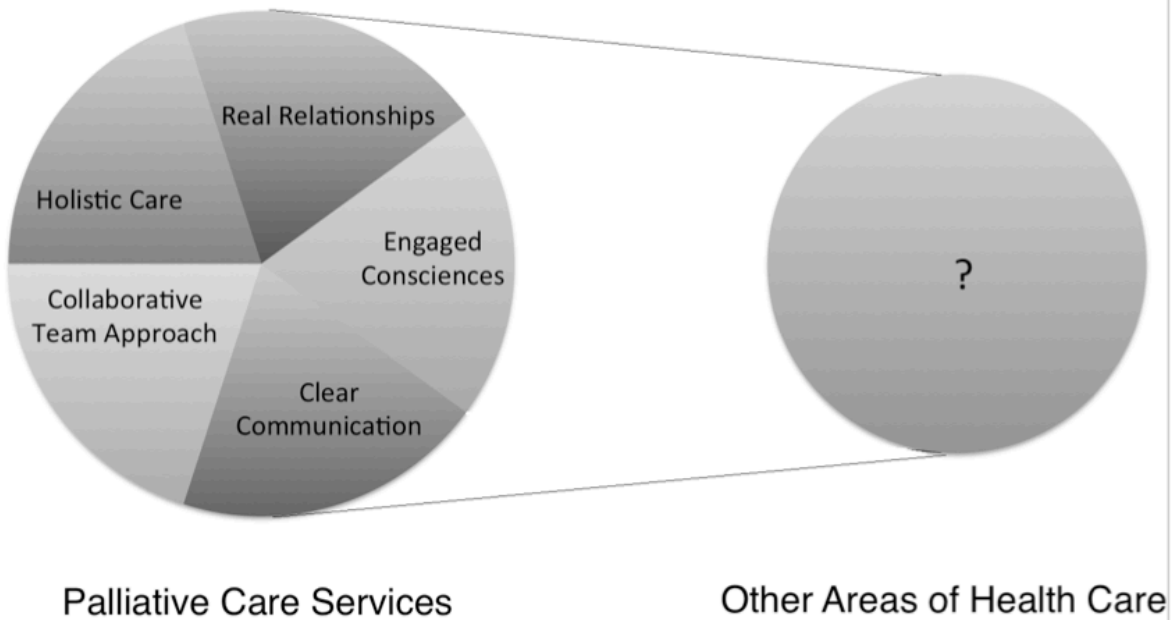
## Quotation #1

“Our success stories always have happy and sad endings. Because usually the stories that I think about that are success stories for me in my work are always patients dying where they want to die - but they still die. So I guess I'm thinking about [a lady] who was on the BiPAP, who got sick quite quickly. And the nurse coordinator who I work with was involved in the case a bit earlier on in the day, and when she first got called in, the family and the patient disagreed about the course of treatment. There were some antibiotics that another [healthcare professional] said would make a big difference to this patient, but the patient was unfortunately too sick to benefit from them. So then the family was very agitated - this woman's children were just desperate to help their mom however they could, and that was causing a lot of friction between the kids and the patient - you add in the husband, who was a second husband, not the kids' father - then you add in the healthcare team who was sending mixed messages to the patient. There was a lot of friction [.....] - luckily a lot of that got sorted out before I walked in - just the luck of the timing of it. Ultimately the patient did not want a lot of aggressive interventions. The patient herself was one of the few people in the room that knew how sick she was and where this was going. And so, again, it was just we took the time to talk with the family; we took the time to listen to the patient - and she told us. And in the end - later on that day - we ended up sedating her and taking the BiPAP mask off. And she died about an hour later. It was a difficult day of negotiations and explanations - going away and giving the family space - and coming back. But in the end she died surrounded by her family who came to support her decision. And she died comfortably. And that was powerful. It was beautiful.”

## Quotation #2

-“[.....] There's more support [on palliative care] for putting into practice compassion and collaboration and how that [is developed]. [.....] On our wall we have a big sign that says, "all about the flow," and I think patient flow and money and reinventing how to do everything [...] - it is about cost. That's the bottom line - and how to get people through. I think we miss the fact that if you have that relationship - if people feel seen and heard - I actually believe in the long run it will benefit the system, but you need the higher ups to make it - not just give lip-service to the value of compassion - but to make it a concrete part of the work that we do.”

## Decision-Making Tools in Health Care





**a. Clear Communication:**

- frequent communication between team members
- frequent communication with patients
- skilled communicators
- clear on the goals of care
- make time and space for discussions
- “being able to listen and communicate with [our] patient is very import to us because otherwise we don't find out what's important to that patient and sometimes we can facilitate - with the other team members - a whole care that takes in that whole person, or that idea of holistic suffering.”

**b. Collaborative Team Approach:**

- trust each others decisions and abilities
- strong leadership from physicians
- consult with each other regarding difficult situations
- “If we don't feel in relationship with the place we work, how can we provide relationship to patients and families?”

**c. Holistic Care:**

- patient and family centered
- see the patient in his or her own story as a person with their own set of relationships
- process oriented
- patients will communicate better when they feel cared for as people, not as diseases
- “None of us really aspires to be ‘the pancreas in [room] 574’”

**d. Real Relationships**

- necessary to establish trust and open up communication
- allows deeper healing on a psychosocial level
- need to bring your whole self to a relationship
- relationship building requires physical space, time, and psychosocial space

**e. Engaged Consciences:**

- the team understood conscience to have three dimensions:
  1. arbiter of right and wrong
  2. instilling conscientiousness
  3. navigation tool
- if they are not allowed to express their consciences in their relationships, health care workers become like robots who cannot build real relationships
- no one can block off certain parts of their conscience and keep others
- “I think conscience drives you to be the best you can be.”

## **Questions and Handouts for Semi-Structured Interpretive Panel 2**

*Explain motivation for project*

**Research Question:** What aspects of palliative care providers' deliberative processes provide insights such as informs the development of policy and/or reflections on the practices of providers in other areas of the healthcare system?

-Or, do any of the tools used in palliative care provide insights that could be useful in the creation of policies, etc. in other areas of the health region?

### **A. Findings: Decision-Making Tools**

Embodied example: Quotation 1

#### **a. Clear Communication:**

- frequent communication between team members
- frequent communication with patients
- skilled communicators
  - in a position where they can be very clear on the goals of care
- make time and space for discussions
- “being able to listen and communicate with [our] patient is very import to us because otherwise we don't find out what's important to that patient and sometimes we can facilitate - with the other team members - a whole care that takes in that whole person - or that idea of holistic suffering.”

#### **b. Collaborative Team Approach:**

- trust each others decisions
- trust each others' ability to connect with a patient, whenever that moment arises
- strong leadership from physicians, who welcome input from other team members
- consult with each other regarding difficult situations
- intentional team building
- “if we don't feel in relationship with the place we work, how can we provide relationship to patients and families?”

#### **c. Holistic Care:**

- patient and family centered
- see the patient in his or her own story as a person with their own set of relationships
  - “none of us really aspires to be ‘the pancreas in [room] 574’”
- process oriented, not task oriented, journeying with patients
- can catch problems earlier because patients will communicate better when they feel team members care about them as people, not as diseases
- team members bring their whole selves to their work, including their conscience

#### **d. Real Relationships**

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- need to bring your whole self to a relationship, not just a professional mask
  - difficult balance between being professional and being authentic
- relationship building requires physical space, time, and psychosocial space

#### **e. Engaged Consciences:**

- the team understood conscience to have three dimensions:
  4. arbiter of right and wrong
  5. instilling conscientiousness
  6. navigation tool
- if they are not allowed to express their consciences in their relationships, health care workers become like robots who cannot build real relationships
- caring, compassionate people need their consciences and cannot block off certain parts of it and keep others
- “I think conscience drives you to be the best you can be.”

1. **To begin with, what are your initial reactions to these results? Are you surprised that the palliative care team places such an emphasis on holistic care?**
2. **Is it fair to say that these first three tools are being promoted through the health region and that they are present in varying degrees in different disciplines?**
3. **In your experience in the health region, do you feel that fostering healthy relationships is a focus of your discussions?**

#### *Quotation 2: Conscience at work*

4. **The palliative care team members viewed their own consciences and the consciences of their team members as an asset in their work. In your experience, are the consciences of health care professionals viewed as an asset to the health region?**

#### **B. Future policy**

##### *Quotation 3: Policy support*

6. **Could the tools used on palliative care provide insight into the practices of healthcare providers in other areas of the healthcare system?**

7. **Could the tools used on palliative care inform the development of future policies?**

**-For example, the health region will likely be crafting new policies around end-of-life care in the near future. How might these policies support holistic care/communication/teamwork?**

#### **C. Practical possibilities**

- have a picture of the patient from when they were healthy next to ever bed
- how to say ‘no’: “That’s the thing - it’s not just a ‘no.’ It’s generally a conversation - it opens the door to a conversation.”
- education on communication skills? – e.g., sit down with patients, frame questions in an accessible way

- assign support staff to specific areas and make them feel part of a team
- encourage creativity
- would electronic records help ensure that these discussions don't have to be rushed over and over again?

**D. Other**

**8. Does the health region have any statistics for patient/family satisfaction in palliative care?**

## Quotation #1

When I was working in the community doing palliative care, [I had] a bereavement call for a gentleman who was 93-years-old, and he used to walk me to my car. When I drove up he would come meet me and walk me in. And he had asked me if I was married, and I said, "no." [...]

So there's two thoughts of training. One would be to say, "and can you tell me why that's important to you?" - and not answer - to totally deflect. But I was going into his home. He was sharing how he'd been married for 65 years, and when I left to go back to school, he walked me out and said - [...] probably the most profound of all the time I'd been with him - he told me that I reminded him of his wife and [.....] he wanted me to get married. He regretted spending so much time away from home and he wanted me to be happy. He wanted me to have a relationship and I think he was trying to teach me that that was more important than work.

So there is being caring and creating a safe space that's very intimate when you're talking about death and dying and your most intimate pieces. And when you are going into people's homes, it's not a clinical setting. There's pictures, there's stories, there's that whole person's life of who they are and how they've become that, and I think they test you to see if they trust you enough to share the vulnerabilities and the things that are most private to them. The psychosocial and the physical are so intertwined [that] you have to have that relationship to be able to do the other pieces no matter [what] your discipline is. No matter whether you're the cleaning staff or the physician or the nurse - you have to have a sense of relationship and trust.

## Quotation #2

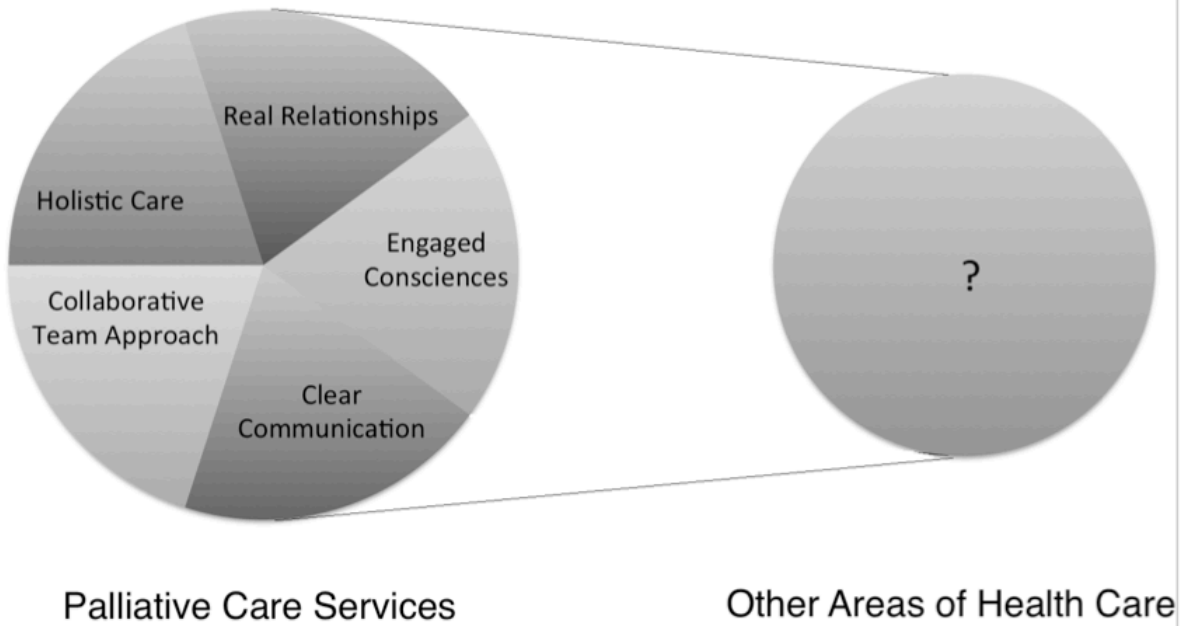
[In one situation], we had trouble getting the family to understand how end-of-life care the [patient] really was. It was hard because I don't think they were as prepared for that client's death [...], because they did not want to hear it. They did not want to hear that she [was dying] - and [I] felt I just did not get the good conversations [I] wanted to get.

So those are hard; those are frustrating. I like to ask myself - and I ask my coworkers and my manager - "is there something I should have done differently? Should we have done something differently?" And I think sometimes [...] in situations like that [...], we actually adjust [our approach] and maybe more than one [team member] will go. So that we can have two different eyes [and] thoughts on what to do in a situation like that because we were both feeling the same way - both [team members] that were going in. But at least you're not doing it alone and at least [I know] it's not [just] me. And [I get] maybe a different angle or a different way of connecting with someone.

## Quotation #3

- "[.....] There's more support [on palliative care] for putting into practice compassion and collaboration and how that [is developed]. [.....] On our wall we have a big sign that says, "all about the flow," and I think patient flow and money and reinventing how to do everything [...] - it is about cost. That's the bottom line - and how to get people through. I think we miss the fact that if you have that relationship - if people feel seen and heard - I actually believe in the long run it will benefit the system, but you need the higher ups to make it - not just give lip-service to the value of compassion - but to make it a concrete part of the work that we do."

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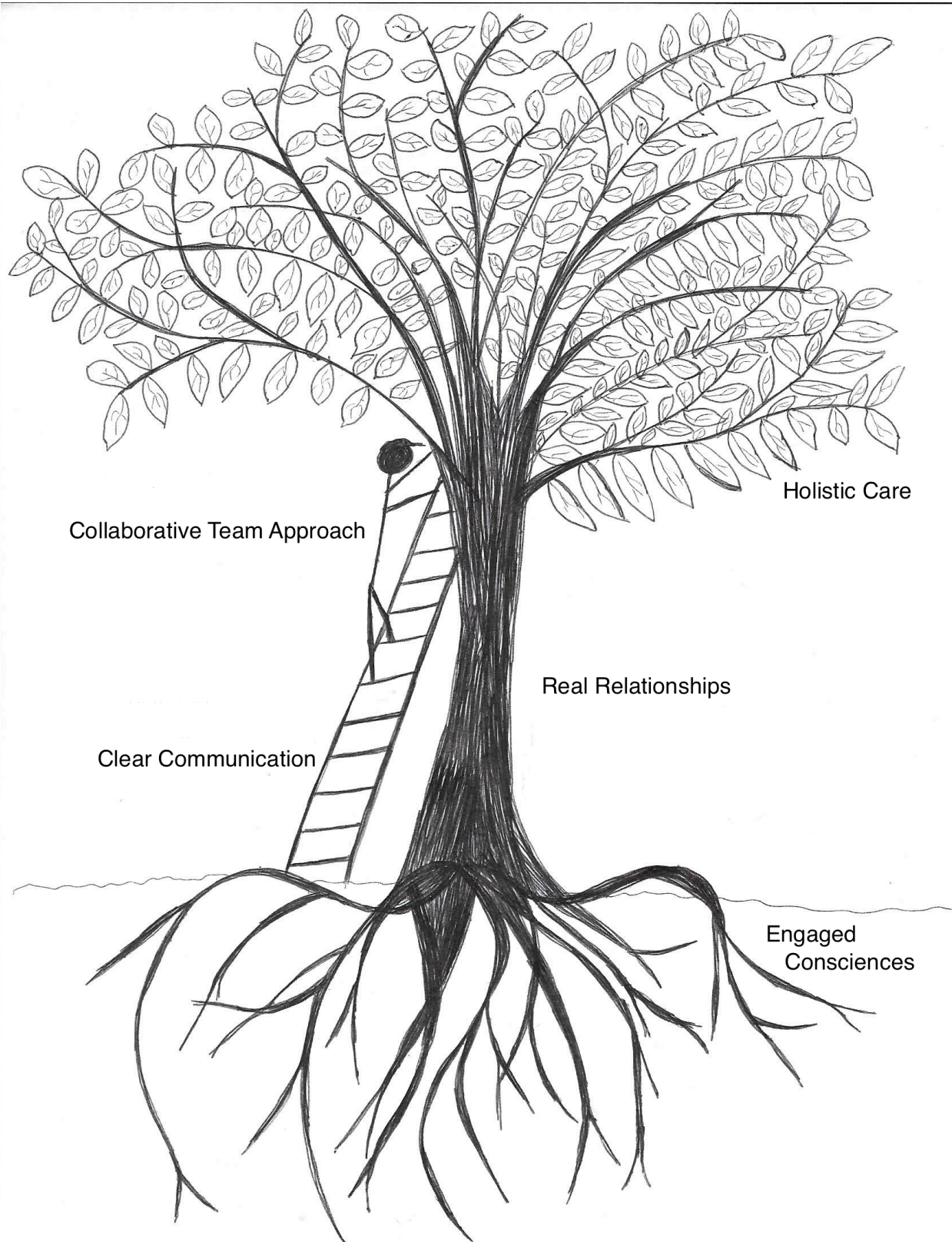
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**Appendix C:**  
**Behavioural Research Ethics Review and**  
**Saskatoon Health Region Operational Approval**



## Application for Behavioural Research Ethics Review

### *Evaluating Applications*

The matters of greatest concern to the Behavioural Research Ethics Board (Beh-REB) are the issues of informed consent of participants, voluntary participation, protection of individual privacy (confidentiality and anonymity), and safeguarding participants from any harmful results due to participation or non-participation in the proposed investigation or research project. Our evaluation of an application is based on the degree to which each of these concerns are satisfied; when filling out the application, researchers are urged to consider these points, and to explain to the Beh-REB the steps they will take to address the concerns. Researchers are also urged to consult the [Tri-Council Policy Statement 2](#) for more information and guidance.

The Beh-REB acknowledges the variety of paradigms and methodologies currently available to researchers, and that each of these paradigms entails its own particular ethical issues. Thus, there may be more than one way to address an ethical issue. Researchers should feel free to suggest alternative approaches or to explain why a particular requirement is not appropriate in the context of a given project.

**\*\*All text boxes will expand once <Enter> is selected or the cursor moves to the next section.\*\***

PART 1: IDENTIFICATION																							
1.1	<b>Project Title</b> <a href="#">GN 1.1</a> Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care																						
1.2	<b>Principal Investigator</b> <a href="#">GN 1.2</a> Full Name: Mary Deutscher Mailing Address: 238 Brookhurst Cres. Saskatoon SK, S7V 1C5 Email: mkd497@mail.usask.ca Phone: (306) 717-6167 NSID number (U of S faculty only):																						
1.3	<b>University/Institutional Affiliation of Principal Investigator</b> <a href="#">GN 1.3</a> Position: Graduate Student Department: Johnson-Shoyama Graduate School of Public Policy Division:																						
1.4	If this is a student/graduate/resident project, please provide the following information: <a href="#">GN 1.4</a> a) Student Name(s) and Student ID or NSID (s): Mary Deutscher 10405714 b) Supervisor Name: Keith Walker																						
1.5	<table style="width: 100%; border-collapse: collapse;"> <tr> <th colspan="2" style="text-align: left; padding: 2px;">Project Personnel (include graduates/post graduates/residents): <a href="#">GN 1.5</a></th> <th style="text-align: center; padding: 2px;">Add Personnel</th> <th style="text-align: center; padding: 2px;">Remove Last</th> </tr> <tr> <td style="width: 50%; padding: 2px;">Full Name: Mary Deutscher</td> <td style="width: 50%; padding: 2px;">Full Name: Keith Walker</td> <td colspan="2"></td> </tr> <tr> <td style="padding: 2px;">Project Position/Role: Principal Investigator</td> <td style="padding: 2px;">Project Position/Role: Faculty Advisor</td> <td colspan="2"></td> </tr> <tr> <td style="padding: 2px;">University/Institutional Affiliation: University of Saskatchewan</td> <td style="padding: 2px;">University/Institutional Affiliation: University of Saskatchewan</td> <td colspan="2"></td> </tr> <tr> <td style="padding: 2px;">Email: mkd497@mail.usask.ca Phone: (306) 717-6167</td> <td style="padding: 2px;">Email: keith.walker@usask.ca Phone: (306) 966-7623</td> <td colspan="2"></td> </tr> </table>			Project Personnel (include graduates/post graduates/residents): <a href="#">GN 1.5</a>		Add Personnel	Remove Last	Full Name: Mary Deutscher	Full Name: Keith Walker			Project Position/Role: Principal Investigator	Project Position/Role: Faculty Advisor			University/Institutional Affiliation: University of Saskatchewan	University/Institutional Affiliation: University of Saskatchewan			Email: mkd497@mail.usask.ca Phone: (306) 717-6167	Email: keith.walker@usask.ca Phone: (306) 966-7623		
Project Personnel (include graduates/post graduates/residents): <a href="#">GN 1.5</a>		Add Personnel	Remove Last																				
Full Name: Mary Deutscher	Full Name: Keith Walker																						
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Email: mkd497@mail.usask.ca Phone: (306) 717-6167	Email: keith.walker@usask.ca Phone: (306) 966-7623																						
1.6	<b>Primary Contact Person for Correspondence (if different than Section 1.2)</b> <a href="#">GN 1.6</a> Full Name: Mailing Address:																						

	Email: <input type="text"/>	Phone: <input type="text"/>						
1.7	Research Site(s) where project will be carried out: <input type="text" value="Location of participant's choosing, Saskatoon Health Region facility"/>							
1.8	1.8.1 Proposed Project Period: <a href="#">GN 1.8</a> From (MM/DD/YY) <input type="text" value="01/01/15"/> To (MM/DD/YY) <input type="text" value="09/01/16"/>							
1.9	<p><b>1.9.1 Has this project applied for and/or received ethical approval from any other Research Ethics Board? Will you be seeking REB approval through the Sask. ethics harmonization process?</b> <a href="#">GN 1.9</a></p> <p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p><b>1.9.2 Please be advised that approvals may need to be sought if you are collecting data from schools, within health regions and may be required from other organizations, agencies, or community groups. Will you be contacting potential participants or collecting data from any such organizations?</b> <a href="#">GN 1.9.2</a></p> <p><input checked="" type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If yes selected then open: Specify where, provide details and submit a copy of the certificate or letter of approval (when obtained). Please provide justification if you do not plan to seek approval.</p> <p><b>This research will collect data within the Saskatoon Health Region (SHR). Letter of approval is pending.</b></p>							
1.10	<p>1.10.1 Status of Funds: <a href="#">GN 1.10</a> <input type="checkbox"/> Awarded <input checked="" type="checkbox"/> Pending <input type="checkbox"/> Unfunded</p> <p>1.10.2 Provide name of funding source: <input type="text" value="Canadian Institute of Health Research (CIHR)"/></p> <p>1.10.3 Source of Funds:</p> <table border="0"> <tr> <td><input type="checkbox"/> Industry</td> <td><input type="checkbox"/> National Institute of Health (NIH)</td> </tr> <tr> <td><input checked="" type="checkbox"/> Tri-Council Grant</td> <td><input type="checkbox"/> Cooperative Group (NCIC, COG, RTOG)</td> </tr> <tr> <td><input type="checkbox"/> Not-for-Profit Foundation</td> <td><input type="checkbox"/> Internally funded</td> </tr> </table>		<input type="checkbox"/> Industry	<input type="checkbox"/> National Institute of Health (NIH)	<input checked="" type="checkbox"/> Tri-Council Grant	<input type="checkbox"/> Cooperative Group (NCIC, COG, RTOG)	<input type="checkbox"/> Not-for-Profit Foundation	<input type="checkbox"/> Internally funded
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<input type="checkbox"/> Not-for-Profit Foundation	<input type="checkbox"/> Internally funded							
11.1	Name of Sponsor if different from above funding source: <input type="text"/>							

## PART 2: CONFLICT OF INTEREST

2.1	<p><b>2.1.1 Is there any real, potential or perceived conflict of interest (any personal or financial interest in the conduct or outcome of this project)?</b> <a href="#">GN 2.1</a></p> <p><input type="text" value="No"/></p> <p><b>2.1.2 Will any of the researcher(s), members of the research team and/or their immediate family members:</b></p> <ul style="list-style-type: none"> <li>- Receive personal benefits in connection with this project over and above the direct costs of conducting the project, such as remuneration or employment?</li> <li>- Receive significant payments of other sorts from the sponsor such as grants, compensation in the form of equipment or supplies or retainers for ongoing consultation and honoraria?</li> <li>- Have a non-financial relationship with a sponsor (such as unpaid consultant, board membership, advisor or other non-financial interest)?</li> <li>- Have any direct involvement with the sponsor such as stock ownership, stock options or board membership.</li> <li>- Hold patents, trademarks, copyrights, licensing agreements or intellectual property rights linked in any way to this project or the sponsor?</li> <li>- Have any other relationship, financial or non-financial, that if not disclosed, could be construed as a conflict of interest?</li> </ul> <p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p>
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## PART 3: BRIEF OVERVIEW OF RESEARCH PROJECT

3.1	<p><b>Briefly describe the project, its objectives and potential significance (250-500 words):</b> <a href="#">GN 3.1</a></p> <p>The creation of policies to mediate conscientious disagreements between healthcare professionals and those they serve presents a unique challenge for Canadian policy makers. Such policies must be underpinned by a clear understanding of the concept of conscience and its role in the relationships found throughout the Canadian healthcare system. As policies related to conscience are developed, policy makers will need to investigate not only cases where conscientious disagreements have escalated into conflicts, but also the many situations in which healthcare professionals and their patients have been able to find positive resolutions. I observe that palliative care teams across the world are noteworthy because they achieve a high degree of patient satisfaction even though they are regularly exposed to the ethical challenges inherent at the end-of-life from which conscientious disagreements are likely to arise. This study will use a narrative inquiry method to articulate what deliberative</p>
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	<p>processes, if any, lead to the positive outcomes witnessed in palliative care. This project will then investigate whether these processes may inform the development of a policy framework that facilitates the positive resolution of conscientious disagreements in other areas of the healthcare system. Such a framework could enhance the organizational culture of healthcare institutions, helping them to avoid the financial and emotional costs of protracted court cases and enhancing the relationships between healthcare professionals and patients.</p>												
3.2	<p><b>Provide a description of research design and methods to be used:</b> <a href="#">GN 3.2</a></p> <p>The research will be conducted in three phases. First, over a period of six to eight weeks, I intend to conduct one hour-long semi-structured interview with each of up to 10 members of the Saskatoon Health Region's (SHR) palliative care team. Following the interviews, participants will be asked to participate in one or two focus groups designed to explore the perceptions of the collective deliberative processes of the palliative care team. Transcripts of the interviews and focus groups will be analyzed using open and axial coding. In the second phase, this analysis will be reported to an interpretive panel (a type of focus group) who will comment on whether the deliberative processes identified in palliative care may inform the development of a policy framework that facilitates the positive resolution of conscientious disagreements in other areas of the healthcare system. This meeting will be transcribed and analyzed using open and axial coding. In the third phase of this project, the data collected in the first two phases will be used to determine whether the deliberative processes of palliative care could inform the creation of policy in other areas of the healthcare system.</p>												
3.3	<p><b>Provide details regarding the duration and location of data collection event(s):</b> <a href="#">GN 3.3</a></p> <p>Phase 1: Over a period of six to eight weeks, I will conduct an hour-long semi-structured interview with each of up to ten participants. These sessions will be conducted away from the hospital, outside of work hours and at a location of the participant's choosing to provide participants with an appropriate space to reflect on their experiences. The interviews will be followed by one or two focus groups, which will be asked to convene for one hour at a health region facility. These interviews and focus group sessions will be recorded and transcribed. A follow up interview by phone, e-mail or in person may be required.</p> <p>Phase 2: I will purposely select a group of up to five managers and senior leaders from the SHR to interpret the data I have collected and analyzed in the first phase of my research. This interpretive panel, which is a type of focus group, will be asked to convene for one hour at a SHR facility.</p> <table border="0"> <tr> <td><input type="checkbox"/> Questionnaire</td> <td><input type="checkbox"/> Participant Observation</td> </tr> <tr> <td><input checked="" type="checkbox"/> Individual Interviews</td> <td><input checked="" type="checkbox"/> Focus Groups</td> </tr> <tr> <td><input type="checkbox"/> Group Interview</td> <td><input type="checkbox"/> Non-invasive physical measurements</td> </tr> <tr> <td><input type="checkbox"/> Video/audio recording</td> <td><input type="checkbox"/> Secondary use of data or analysis of existing data</td> </tr> <tr> <td><input type="checkbox"/> Home Visits</td> <td><input type="checkbox"/> Ethnography</td> </tr> <tr> <td><input type="checkbox"/> Other: _____</td> <td></td> </tr> </table>	<input type="checkbox"/> Questionnaire	<input type="checkbox"/> Participant Observation	<input checked="" type="checkbox"/> Individual Interviews	<input checked="" type="checkbox"/> Focus Groups	<input type="checkbox"/> Group Interview	<input type="checkbox"/> Non-invasive physical measurements	<input type="checkbox"/> Video/audio recording	<input type="checkbox"/> Secondary use of data or analysis of existing data	<input type="checkbox"/> Home Visits	<input type="checkbox"/> Ethnography	<input type="checkbox"/> Other: _____	
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<input type="checkbox"/> Other: _____													

#### PART 4: PROJECT DETAILS

4.1	<p><b>4.1.1 Will you have any internet-based interaction with participants?</b> <a href="#">GN 4.1</a></p> <p><input checked="" type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p><b>4.1.2 If you are using a third party research tool, website survey software, transaction log tools, screen capturing software, or masked survey sites, how will you ensure the security of data gathered at that site?</b></p> <p>I will be using NVivo software and will store all data on a password protected thumb drive.</p> <p><b>4.1.3 Describe how permission to use any third party owned site(s) will be obtained, if applicable:</b></p> <p>I will receive permission from the director of palliative care to use sites at the Saskatoon Health Region.</p> <p><b>4.1.4 How will you protect the privacy and confidentiality of participants who may be identified by email addresses, IP addresses, and other identifying information that may be captured by the system during your interactions with these participants?</b></p> <p>Any e-mail communication with participants will be through the secure servers of the Saskatoon Health Region and the University of Saskatchewan.</p> <p><b>4.1.5 If you do not plan to identify yourself and your position as a researcher to the participants, from the onset of the research study, explain why you are not doing so, at what point you will disclose that you are a researcher, provide details of debriefing procedures, if any, and if participants will be given a way to opt out, if applicable:</b></p> <p>I plan to identify myself as a researcher.</p>
4.2	<p><b>4.2.1 Will your research involve Aboriginal Peoples including First Nations, Inuit and Métis peoples?</b> <a href="#">GN 4.2</a></p> <p><input type="checkbox"/> Yes    <input checked="" type="checkbox"/> No</p>

4.3	4.3.1 Will the project involve community-based participatory research? <a href="#">GN 4.3</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.4	Will deception of any kind be necessary in this project? <a href="#">GN 4.4</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.5	Indicate how the participants will be debriefed following their participation (if applicable), and describe how the information on the results of the research will be made available to participants once the study has ended. Debriefing is particularly important if deception has been used. <a href="#">GN 4.5</a> Participants will be informed of the goals of this research before they consent to participate. Following the study, findings will be included in my doctoral thesis, which participants will be able to access through the U of S library.
4.6	Will participants be compensated? <a href="#">GN 4.6</a> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4.7	4.7.1 Will participants be anonymous in the data gathering phase of the study? (Anonymous means that no link can be established between the participant and the research - no one including the researcher knows who has participated in the research): <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No 4.7.2 Will the confidentiality of participants and their data be protected? (Confidentiality means that no link can be established between the collected information and the participant's identity) <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No 4.7.3 If yes, are there any limits to confidentiality: <input checked="" type="checkbox"/> Limits due to the nature of group activities (e.g. focus groups): the researcher cannot guarantee confidentiality <input checked="" type="checkbox"/> Limits due to context: individual participants could be identified because of the nature or size of the sample or because of their relationship with the researcher. <input checked="" type="checkbox"/> Limits due to selection: procedures for recruiting or selecting participants may compromise the confidentiality of participants (e.g. participants are referred to the study by a person outside the research team) <input type="checkbox"/> Other:

## PART 5: ESTIMATION OF RISKS AND BENEFITS

5.1	5.1.1 Do you consider this project to be: <a href="#">GN 5.1</a> <input checked="" type="checkbox"/> Minimal Risk <input type="checkbox"/> Above Minimal Risk 5.1.2 Indicate if the participants might experience any of the following: Risk of psychological or emotional harm or discomfort (e.g. trauma, anxiety, stress) The participants in this study are trained professionals who are experienced in dealing with the emotional challenges of healthcare. Legal repercussions for participating in the study (e.g. possibility of being sued, charged with criminal activity, disclosure of past or future criminal activities, etc.) No. Social repercussions (e.g. ostracized, being negatively judged by peers or employer, fired from your job) No. Risk of physical harm or discomfort (e.g. falling, muscle pain, tiredness, weakness, nausea) No. 5.1.3 Describe how the risk will be managed (including an explanation as to why an alternative approached could not be used). If appropriate, identify any resources, e.g. physician or counselor, to which participants can be referred. <a href="#">GN 5.1.3</a> N/A 5.1.4 If above minimal risk, what are the likely benefits of the research to the researcher, participant, the research community and society that would justify asking participants to participate? <a href="#">GN 5.1.4</a> N/A
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PART 6: PARTICIPANT RECRUITMENT	
	Describe the participants and the criteria for their inclusion or exclusion. Indicate the number of participants and a brief rationale for the intended number of participants: <a href="#">GN 6.1</a>
6.1	<p>In the first phase of my research I will use a narrative inquiry method to record the experiences of members of the PCS team, choosing a maximum of ten individuals to ensure the experiences of each interviewee are explored in depth. This group will be purposely selected with help from the team's director and manager to include participants from various healthcare professions with a range of experience. This diversity should provide a comprehensive understanding of the deliberative processes used by the team as a whole.</p> <p>In the second phase, the analyzed data from phase one will inform the purposeful selection of a group of up to five members of the SHR's management and senior leadership. This manageable group size should be able to provide meaningful feedback.</p>
6.2	<p><b>6.2.1 Provide a detailed description of the method of recruitment.</b> <a href="#">GN 6.2</a>          With the assistance of the palliative care director and manager, I will select a group of palliative care team members to approach for participation in this study. Each participant will be provided a letter of initial contact (attached). Of the team members who respond affirmatively, I will select up to ten individuals to interview.          In phase two, I will contact members of the SHR's senior leadership and management to request their participation in the interpretive panel using the letter of initial contact (attached).</p> <p><b>6.2.2 How will prospective participants be identified?</b>          Prospective participants will be identified through the palliative care director.</p> <p><b>6.2.3 Who will contact prospective participants? Describe the source of the contact information, how they will be contacted and as applicable, who originally collected the contact information. Ensure any letters of initial contact or other recruitment materials are attached, e.g. advertisements, flyers, telephone script, etc.</b>          The letter of initial contact is attached, and will be distributed through the palliative care director in phase one. I will distribute the letter myself in phase two.</p>
6.3	<p>In cases where the research involves special or vulnerable populations, distinct cultural groups, or in cases where the research is above minimal risk, the researcher should describe their experience or training in working with the population. If none of these criteria apply, this section may be omitted. <a href="#">GN 6.3</a></p> <p>N/A</p>
6.4	<p>Where relevant, please explain any relationship (pre-existing, current or expected to have) between the researcher(s) and the researched (e.g. instructor-student, manager-employee, co-workers, family members/intimate relationships, etc). Please pay special attention to relationships in which there may be a power differential. Describe any safeguards and procedures to prevent possible undue influence, coercion or inducement. <a href="#">GN 6.4</a></p> <p>N/A</p>

PART 7: CONSENT PROCESS	
	Describe the process that will be used to obtain informed consent. Please note that it is the content of the consent, not the format that is important. If the research involves collection of personally identifiable information from a research participant or extraction of personally identifiable information from an existing database, please describe how consent from the individuals or authorization from the data custodian will be obtained. If there will be no written consent, please provide a rationale for oral or implied consent (e.g., cultural appropriateness, online questionnaire, etc.) and explain how consent will be recorded.
7.1	<p><b>7.1.1 Describe the consent process.</b> <a href="#">GN 7.1</a>          Participants will be provided with a consent form via e-mail prior to their interview or participation in the interpretation panel. This form will be signed on the day of the interview/panel.</p> <p><b>7.1.2 Who will ask for consent?</b>          The primary researcher will ask for consent prior to the interview/panel.</p> <p><b>7.1.3 Where, and under what circumstances will consent be obtained?</b>          Consent will be obtained by the researcher at the location of the first interview/panel before proceeding with the session.</p> <p><b>7.1.4 Describe any situation in which the renewal of consent for this research might be appropriate and how this would take place (e.g. longitudinal studies, multiple data collection events, etc.).</b>          N/A</p>
7.2	<p>If any or all of the participants are children and/or are not competent to consent, describe the process by which capacity/competency will be assessed, the proposed alternate source of consent - including any permission/information letter to be provided to the person(s) providing the alternate consent - as well as the assent process for participants. <a href="#">GN 7.2</a></p> <p>N/A</p>

7.3	Describe your plans for providing project results to the participant? <a href="#">GN 7.3</a> Participants will be directed to the University of Saskatchewan website to view the complete PhD projected once it has been defended.
7.4	How and when are participants informed of the right to withdraw? What procedures will be followed for participants who wish to withdraw at any point during the study? <a href="#">GN 7.4</a> All participants will be informed of their right to withdraw both in the initial letter of contact and during the consent process. In phase 1, participants will retain the right to withdraw until they approve the transcript of their interview for use. They will be able to withdraw from the focus group until the session begins. In phase 2, participants may withdraw at any point prior to the beginning of the panel session. If a participant wishes to withdraw, any data collected regarding that participant will be destroyed.

## PART 8: DATA SECURITY AND STORAGE

Indicate the procedures you plan to implement to safeguard and store the data. Identify the person who will be assuming responsibility for data storage (University regulations require the researcher or the supervisor, in the case of student research, to securely store the data at the University of Saskatchewan for a minimum of five years upon the completion of the study - ([Procedures for Stewardship of Research Records at the University of Saskatchewan 2010.](#)))

8.1	Who will conduct the data collection? <a href="#">GN 8.1</a> The primary researcher (Mary Deutscher)
8.2	Who will have access to the original data of the study? <a href="#">GN 8.2</a> The primary research (Mary Deutscher) and the faculty supervisor (Keith Walker)
8.3	How will confidentiality of original data be maintained as well as preserving or destroying data after the research is completed. For all data (e.g. paper records, audio or visual recordings, electronic recordings), indicate the: <a href="#">GN 8.3</a>
	8.3.1 Person responsible for data storage: The primary researcher (Mary Deutscher)
	8.3.2 Data security during transportation from collection site: Data will be transported on a secure thumb drive.
	8.3.3 Means and location of storage (e.g. a locked filing cabinet, password protected computer files, encryption): The thumb drive will be password protected.
	8.3.4 Time duration of storage (Must be > 5 Years): 6 Years
8.4	8.3.5 Final disposition (archive, shredding, electronic file deletion): electronic file deletion
	Indicate how the data collected is intended to be used (thesis, journal articles, conference presentation, media, etc). <a href="#">GN 8.4</a> PhD thesis, journal articles, conference presentations



## PART 9: Declaration by Principal Investigator (or Supervisor for student projects)

### Project Title

Clear policy, clear conscience: An analysis of conscience in Canadian healthcare

- I confirm that the information provided in this application is complete and correct.
- I accept responsibility for the ethical conduct of this project and for the protection of the rights and welfare of the human participants who are directly or indirectly involved in this project.
- I will comply with all policies and guidelines of the University and Health Region/affiliated institutions where this project will be conducted, as well as with all applicable federal and provincial laws regarding the protection of human participants in research.
- I will ensure that project personnel are qualified, appropriately trained and will adhere to the provisions of the REB-approved application.
- I certify that any significant changes to the project, including the proposed method, consent process or recruitment procedures, will be reported to the Research Ethics Board for consideration in advance of its implementation.
- I certify that a status report will be submitted to the Research Ethics Board for consideration within one month of the current expiry date each year the project remains open, and upon project completion.
- If personal health information is requested, I assure that it is the minimum necessary to meet the research objective and will not be reused or disclosed to any parties other than those described in the REB-approved application, except as required by law.
- I confirm that adequate resources to protect participants (i.e., personnel, funding, time, equipment and space) are in place.
- I understand that if the contract or grant related to this research project is being reviewed by the University or Health Region, a copy of the ethics application inclusive of the consent document(s), may be forwarded to the person responsible for the review of the contract or grant.
- I understand that if the project involves Health Region resources or facilities, a copy of the ethics application may be forwarded to the Health Region research coordinator to facilitate operational approval.

\_\_\_\_\_  
Signature of Principal Investigator and/or  
Supervisor

\_\_\_\_\_  
Printed Name of Principal Investigator and/or  
Supervisor

\_\_\_\_\_  
Date (MM/DD/YY)

\_\_\_\_\_  
Signature of Student Investigator

\_\_\_\_\_  
Printed Name of Student Investigator

\_\_\_\_\_  
Date (MM/DD/YY)

**Department Head (UofS and RQHR only) :** The signature/approval of the Department/Administrative Unit acknowledges that he/she is aware of and supports the research activity described in the proposal.

\_\_\_\_\_  
Signature of Department Head

\_\_\_\_\_  
Printed Name of Department Head

\_\_\_\_\_  
Date (MM/DD/YY)

**SECTION 10: APPENDICES [GN 10](#)**

Document	Included?	Description
Recruit Material(s)	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
Letter (s) of Initial Contact	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	Please see attached form.
Consent Form(s)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	Please see attached consent form.
Assent Form(s)	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
Research Tool(s) (e.g. Questionnaires, focus group guides, interview scripts, etc.)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	Please see attached list of potential questions.
Transcript Release Form(s)	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> N/A	Please see attached transcript release form.
RQHR Operational/Departmental Approval Form	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	
Other (please specify): <div style="border: 1px solid black; height: 15px; width: 100%;"></div>	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> N/A	

RE: BEH 15-17

Deutscher, Mary

Wed 3/4/2015 11:15 AM

To: Radcliffe, Beryl <beryl.radcliffe@usask.ca>; Walker, Keith <keith.walker@usask.ca>;

📎 1 attachment

Ethics Attachments.docx

Hello Beryl,

I apologize for how long it has taken me to reply, but please find my responses to your questions in green in the email below. I have attached a file with my updated forms to this e-mail. I believe Keith Walker will be in touch soon to confirm his support for the application.

I look forward to hearing from you again!  
Mary

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**From:** Radcliffe, Beryl  
**Sent:** Monday, February 02, 2015 12:16 PM  
**To:** Walker, Keith  
**Cc:** Deutscher, Mary  
**Subject:** BEH 15-17

Thank you for your application to the Behavioural Research Ethics Board for your project entitled: "Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care" (Beh 15-17). The Beh-REB has the following minor questions that need to be addressed:

**Application for Behavioural Research Ethics Review:** Please note that the application doesn't support highlighting or bolding so responses to the questions below can be addressed within a return email. **Please don't resubmit the application.**

1.2: Please note the University of Saskatchewan requires that the supervisor is listed as the Principal Investigator [PI] and ultimately responsible for the research. Please confirm.

Yes, Dr. Keith Walker is the principle investigator.

1.4: All students affiliated with the U of S conducting human research are required to complete [The TCPS 2 Tutorial Course on Research Ethics \(CORE\)](#). Please confirm the student's completion.

This course has been completed by the student.

3.2 and 3.3: States interview participants will be asked to participate in either one or two focus groups. Please clarify the number of focus groups the participant is expected to participate in. The contact letter and consent form seems to imply only one focus group.

Participants will be asked to participate in one focus group.

3.3: Video/audio recording box was not selected, however the interview, focus group, and interpretive panel discussion group will be audio-recorded. Please confirm.

Yes it will be audio-recorded.

4.1: Sections 6 and 7 indicates that e-mail will be used to interact with participants. Please ensure no group emails are sent to the participants and that the emails will be securely stored separately from the data. Misdirected emails have been the cause of privacy breaches and caution is advised. Secure storage of e-mail addresses is also advised.

Participants will be contacted individually. The security steps outlined above will be followed.

4.5: Please consider a mechanism to provide the results of the research to participants other than reviewing the student's thesis once posted to the U of S website. A plain language report shows respect for participant's time and possibly provide some degree of empowerment that they were able to contribute.

Participants will be provided with a plain language report.

4.7.1: Participants are listed as not being anonymous in the data gathering phase. Please ensure the limitations cited in the application are clearly indicated and described in the consent.

The consent form has been updated and is attached to this e-mail.

6.1-3.3: States up to 5 managers and senior leaders from SHR will be interpreting the data of the first phase (individual interviews and focus group). As these members of the panel will possibly know the participants personally through their PCS team relationships, please discuss the strategy to ensure confidentiality of the participant. Please ensure any limitations to confidentiality are listed in the consent.

The consent form has been updated and is attached to this e-mail. Although participants' names will not be included in the report to the interpretive panel, there will be limitations to confidentiality due to prior relationships between members of the panel and members of the PCS team. These limitations are articulated in the consent form.

6.2.1: Will the invitation to participate letter be sent to the entire PCS team by their director/manager? If yes, how many potential participants are expected? 6.1, states up to a maximum of ten individuals from the PCS team will be selected. How will these individuals be selected if more than ten shown interest in participating?

The invitation to participate will be sent only to those individuals who are selected with the help of the director/manager. The letter will initially be sent to 10 members of the team, and if there are too few participants from this group, the letter will be sent to others as needed. The letter of invitation has been updated and is attached to this e-mail.

6.2: If the participant's team director or manager is assisting with selecting participants, how will any possible coercion be minimized in the recruitment strategies (e.g. nature of the power relationships between the PCS director/manager who would identify and initiate first contact with potential PCS team

participants)?

The letter of initial contact (which will be distributed by the manager/director) has been revised to include a statement clarifying that participation is voluntary, and that if they choose not to participate this will not affect their employment or professional standings.

### 8.3: Data Storage and Security:

8.3.1: The long term storage of data is the responsibility of the Principal Investigator. Please confirm.

Yes.

8.3.2: Please explain how data will be safeguarded while in the field. It is our preference that data be uploaded to a network or cloud rather than being stored on a machine or portable storage device. If data is/has to be stored on a machine or portable storage device please ensure when possible it is password protected and encrypted. Please confirm.

Data will be stored on a password protected USB drive and uploaded to the secure PAWS Cabinet as a backup.

8.3.3: Please confirm the location of storage both paper and electronic.

Electronic data will be stored on a password protected USB drive and in the PAWS Cabinet. Paper data will be stored in a locked filing cabinet in Keith Walker's office.

8.3.3: Please ensure consent forms are kept separate from the data. A reminder that storing data on a password secured computer may still be subject to data loss. All faculty, staff and students have access to the University of Saskatchewan secure Cabinet on [PAWS](#) and it is recommended this site be used as a backup.

Noted.

8.3.5: Reference to electronic file deletion only. Please clarify disposition of the audio-recordings and all paper documents (i.e. consent forms).

Audio-recordings and other electronic files will be permanently deleted. Paper documents will be shredded.

8.3.5: Please ensure that data is not only deleted but also ensure that it will be not be recoverable.

Deleted data will not be recoverable.

### Letter of Initial Contact (Interview and Focus Group)

Spelling error "Lettre" in header. Please revise.

Done.

As a suggestion, to include a statement clarifying that participation is voluntary, and that if they choose not to participate this will not affect their employment or professional standings (given it will be distributed by their director/manager of the PCR team).

The revised letter of initial contact includes this statement.

You may consider including that this study has been reviewed by, and received approval through, the Behavioural Research Ethics office, University of Saskatchewan.

The revised letter of initial contact includes this statement.

In addition to the student, the PI (supervisor) should also be listed as a contact.

The revised letter of initial contact includes the PI as a contact.

**Letter of Initial Contact (Interpretive Panel)**

Spelling error "Lettre" in header. Please revise.

Done.

To assure potential participation is seen as voluntary, please ensure a statement clarifying that participation is voluntary, and that if they choose not to participate this will not affect their employment or professional standings.

The revised letter of initial contact includes this statement.

You may consider including that this study has been reviewed by, and received approval through, the Behavioural Research Ethics office, University of Saskatchewan

The revised letter of initial contact includes this statement.

In addition to the student, the PI (supervisor) should also be listed as a contact.

The revised letter of initial contact includes the PI as a contact.

**Participant Consent Form (Interview and Focus Group): [You may want to consider separate consents, one for the interview and one for the focus groups]**

The student researcher's phone number listed is 306-717-6167. We recommend that you use a U of S land line if possible as the contact phone number for participants rather than your personal phone line. A secure phone line with a password protected voice mail at the U of S should be provided for the researcher's contact. Please revise the consent form accordingly.

The student researcher does not have a U of S land line, but voicemail is password protected at the number listed.

Please review the form and rephrase to remove "I" to "the researcher".

Done.

**Procedures:**

Provide further clarify the number of interviews and focus groups. In this section it refers to the interview as "sessions" and focus group as "focus groups". Please make it clear the expectation of the participant.

The consent form has been broken into two forms: interview and focus group. This should clarify the expectations of the participants in each phase. There will be one focus group.

A suggestion for ease of reading would be to separate into two different paragraphs – one to describe the interview and one to describe the focus group.

The paragraphs have been separated.

Please include a section on "Storage of Data". In this section include how the data will be stored (paper, audio-recordings, electronic, e-mails and contact information) with whom and how long. When data is no longer required, provide details in how the data will be destroyed. Please include that the signed consent forms will be stored separately from the data.

The revised consent forms includes this section.



Right to Withdraw: Please review this section and re-phrase to ensure participants are clear at each stage (interview and focus group) the limitations and restrictions on withdrawal both of themselves as a participant and their data. In a focus group, how will you manage if not all participants agree to audio-recording, or one participant asks to have the recorder turned off? Focus group data is difficult when trying to identifying individual participants who may choose to withdraw. One option to consider here is an explanation as part of the consent process that full withdrawal is only possible before the focus group begins, and that a participant has a right to either leave a focus group or decline to participate in parts of the discussion. Should a participant wish to leave, the contributions made to the point of withdrawal cannot be removed. There is also methodological rationale for this, since the integrity of the discussion is challenged if part of the discussion is afterwards removed –significantly impacting the quality of the data and the analysis.

The revised consent form is separated into two forms: interview and focus group. This should clarify the right to withdraw.

Follow-up: As suggested above, please consider making a plain language report available as well.

The revised consent form includes this statement.

**Participant Consent Form (Interpretive Panel):**

The student researcher's phone number listed is 306-717-6167. We recommend that you use a U of S land line if possible as the contact phone number for participants rather than your personal phone line. A secure phone line with a password protected voice mail at the U of S should be provided for the researcher's contact. Please revise the consent form accordingly.

The student researcher does not have a U of S land line, but voicemail is password protected at the number listed.

Please review the form and rephrase to remove "I" to "the researcher".

Done.

Please include a section on "Storage of Data". In this section include how the data will be stored (paper, audio-recordings, electronic, e-mails and contact information) with whom and how long. When data is no longer required, provide details in how the data will be destroyed. Please include that the signed consent forms will be stored separately from the data.

The revised consent form includes this section.

Right to Withdraw: Please review this section and re-phrase to ensure participants are clear the limitations and restrictions on withdrawal both of themselves as a participant and their data. In a focus group, how will you manage if not all participants agree to audio-recording, or one participant asks to have the recorder turned off? Focus group data is difficult when trying to identifying individual participants who may choose to withdraw. One option to consider here is an explanation as part of the consent process that full withdrawal is only possible before or during the focus, and that a participant has a right to either leave a focus group or decline to participate in parts of the discussion. Should a participant wish to leave, the contributions made to the point of withdrawal cannot be removed. There is also methodological rationale for this, since the integrity of the discussion is challenged if part of the discussion is afterwards removed –significantly impacting the quality of the data and the analysis.

The revised form clarifies this section.

Please note that your research project cannot begin until you have received a certificate of approval from the Behavioural Research Ethics Board.

Please highlight or mark in bold all revisions to the above letter(s) and form(s) and send electronically to [beryl.radcliffe@usask.ca](mailto:beryl.radcliffe@usask.ca).

If you have any questions, comments or concerns, you can contact me at any time at 306-966-2084.

 **Beryl Radcliffe B. Sc. CCRP**

Ethics Specialist (Behavioural)

Research Ethics Office

Phone: 306-966-2084



1602 - 110 Gymnasium Place  
Saskatoon, Saskatchewan S7N 0W9

[NRC/FBI Building](#) (map available)





UNIVERSITY OF  
SASKATCHEWAN

Associate Vice-President Research – Health  
(University of Saskatchewan)  
Vice-President Research and Innovation  
(Saskatoon Health Region)

Attention: Research Approval Coordinator  
Post Office Box 118 or Facsimile (306)978-8301  
Royal University Hospital  
103 Hospital Drive  
Saskatoon, SK S7N 0W8

**Saskatoon Health Region: Application for Operational Approval to Conduct a Research Study**

If you have any questions regarding how to complete this form please contact the Research Approval Coordinator at (306)655-1442 or email:

Project Title: **Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care**

REB# and/or protocol number (if available at time of submission): **15-17**

Name/title of Principal Investigator: **Dr. Keith Walker**

Telephone number: **(306) 966-7623**

Email address: **keith.walker@usask.ca**

**Declaration by Principal Investigator**

By signing below, I certify that all information provided herein is accurate and complete. If circumstances should arise that materially affects the accuracy and completeness of the information provided, I will immediately report the new information in writing. I agree to abide to all applicable laws, regulations and international guidelines concerning the conduct of research with humans. I have read, understood and will abide to the Saskatoon Health Region Research Policy (7311-100-001). (<https://www.saskatoonhealthregion.ca/about/RWPolicies/7311-100-001.pdf>)

As per Section 29 of the Health Information Protection Act (HIPA) the Principal Investigator will comply with HIPA by agreeing:

- that the data/ information being disclosed by the Saskatoon Health Region for the purposes of the research project may not be disclosed to anyone else;
- that the data/ information being disclosed by the Saskatoon Health Region for the purposes of the research project may only be used for the purposes described in the researcher's Research Ethics Board application;
- to take reasonable steps to ensure the security and confidentiality of the information disclosed by the Saskatoon Health Region, as identified in the researcher's Research Ethics Board application;
- to either return to the Saskatoon Health Region or destroy any original records or copies of data/information containing personal health information disclosed by the Saskatoon Health Region or copies made by the researcher of the personal health information disclosed for the purposes of the research, as described in the researcher's Research Ethics Board application;
- to seek additional approval from Saskatoon Health Region for any other use other than that authorized for this research project;
- to notify the Saskatoon Health Region Privacy Officer and the Research Approval Coordinator immediately upon becoming aware that any of the conditions set out in this Agreement have been breached;

In addition to other remedies available, SHR will not provide any further data to the Researcher if any of the conditions set out in this Agreement have been breached and will seize the data already provided. The terms and conditions of this Agreement will be of indefinite duration.

Signature of Principal Investigator: 

Please note, depending on the type of information being disclosed by Saskatoon Health Region for the research project, a separate Data Sharing Agreement/Data Transfer Agreement between Saskatoon Health Region and the researcher/receiving organization may be required.

**Research Study Contact** – Someone from the research study team who will deal with problems and concerns while the research is ongoing.

☐ Same as above

Name/Title: **Mary Deutscher, PhD Candidate**  
 Telephone Number: **(306) 717-6167**  
 Email Address: **mkd497@mail.usask.ca**

**Please Note:** The Research Approval Coordinator may contact the U of S Research Ethics office to obtain a copy of the ethics application and the ethics certificate of approval if not provided with this application.

#### Part One: Study Information

**A.** If this study is occurring in a U of S office/clinic/lab within an SHR facility (for example: RUH) and will not be utilizing SHR resources/programs then please indicate the SHR facility in which the research will be occurring and submit page 1 & 2 of the application: **N/A**

**B.** SHR Data Collection Start Date: **18/05/15**(dd/mm/yy) Anticipated End Date: **30/09/15**(dd/mm/yy)

**C.** Study Participants Include: ☐ Inpatients ☐ Outpatients ☐ Long term care residents  
☒ Staff ☐ Chart review ☐ Other: \_\_\_\_\_

**D.** Anticipated Total Number of Participants: **15**

**E.** Funding source to cover SHR costs\*: \_\_\_\_\_ ☒ not applicable

**F.** Will the study funds be administered by the U of S? ☐ yes ☒ no, specify where funds will be held: **N/A**

**\*Please submit a copy of all SHR departmental study budgets with this application.**

#### DEPARTMENT IMPACT ASSESSMENT

For each of the Saskatoon Health Region departments that are applicable for this research, provide the following impact assessment information OR attach the relevant information about your project:

##### Part Two: Resource Utilization – Clinical Services

Not applicable ☒

Resource utilization refers to the utilization of SHR services for tests/procedures required for clinical research. This applies to standard of care and study specific tests/procedures and includes outpatient and inpatient participants. Please refer to the SHR Operational Approval Guidance Notes for more information or contact the Research Approval Coordinator for assistance.

**Ambulatory Services (e.g. Endoscopy, Pulmonary Function, Sleep Disorder Centre)** Not applicable ☒

Clinic/Site	Services required (e.g. #, procedure, study specific vs. std of care)
<input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH <input type="checkbox"/>	
<input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH <input type="checkbox"/>	

##### Health Records/Strategic Health Information & Performance Support (SHIPS)

Not applicable ☒

Site	Indicate Services required:
<input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH <input type="checkbox"/> other: _____	<input type="checkbox"/> Generation of study subject list for chart pull and review <input type="checkbox"/> Health record charts pulled: number required _____ <input type="checkbox"/> Health record chart information analysis
<input type="checkbox"/> SHIPS (SPH)	SHIPS data request:

**Heart Health Diagnostic Services (e.g. Cardiac Cath Lab/Non-invasive Cardiology)** Not applicable ☒

Service/Site	Services required (e.g. #, study specific vs. std of care)
Cardiac Cath (RUH)	

ECG: <input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH	
Echocardiogram: <input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH	
Other:	

#### Laboratory Medicine Services

Not applicable ☒

**\*\*Please note all studies receiving lab approval are subject to a \$150.00 Lab Utilization Fee\*\***

Division /Site	Services required (e.g. #, study specific tests required; phlebotomy only, phlebotomy and analysis, analysis only; culture of specimen; block pulls; storage of specimen, data, etc.)
Phlebotomy <input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH	
Chemistry <input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH	
Hematology <input type="checkbox"/> RUH <input type="checkbox"/> SCH <input type="checkbox"/> SPH	
Microbiology (RUH)	
Transfusion Medicine (RUH)	
Cytogenetics (RUH)	
Pathology (SCH)	
Lab Information System (SCH)	
Rural Lab:	

#### Medical Imaging and Nuclear Medicine Services ☐ RUH ☐ SCH ☐ SPH

Not applicable ☒

**\*\*Please note all studies receiving medical imaging approval are subject to a \$200.00 Administration Fee\*\***

Procedure	Detail (part of body to be imaged or scanned)- attach imaging protocol if applicable	Services required (e.g. #, std. of care vs. study specific, copy of test result only, copy of test result with radiologist report, etc.)
X-ray		
CT Scan		
MRI		
PET-CT		
Bone Scan		
Bone Density		
Ultrasound		
MUGA		
Other:		

#### Special Services Pharmacy (RUH)

Not applicable ☒

Service	Yes	No
Does the Sponsor Company provide randomization via an interactive voice response system (IVRS)?	<input type="checkbox"/>	<input type="checkbox"/>
Will Pharmacy be required to randomize patients?	<input type="checkbox"/>	<input type="checkbox"/>
Is the company providing all required drugs for free	<input type="checkbox"/>	<input type="checkbox"/>
Is the company reimbursing for pharmaceutical supplies used?	<input type="checkbox"/>	<input type="checkbox"/>
Other pharmacy services required:		

#### Part Three: Program Utilization

Not applicable ☐

Program utilization refers to access to SHR programs for recruitment of study participants (in-patients, out-patients, long term care residents or staff) or if the study will be taking place within a program or accessing data from a program. This applies to clinical and non-clinical research studies.

Please indicate the Program(s) in which the study will be carried out. Specify which unit(s) in the program will be involved and the site(s). For example – General Medicine: 6200 RUH, 5<sup>th</sup> med SPH, 6<sup>th</sup> med SPH.

List all the tasks required by the Program(s) for this study. For example, disbursement of recruitment material, providing data, participating in survey/interview/focus group, SHR staff performing study-related tasks/procedures. Please specify which tasks are study specific.

The approval from the Manager for the unit(s) involved is required. Please refer to the Operational Approval Guidance Notes for more information or contact the Research Approval Coordinator for assistance.

**Acute Care Services:**

Not applicable ☐

- ☐ Children's Services: \_\_\_\_\_
- ☐ Critical Care Services (ICU/Progressive Care Unit): \_\_\_\_\_
- ☐ Emergency (specify site): \_\_\_\_\_
- ☐ General Medicine: \_\_\_\_\_
- ☐ Geriatrics: \_\_\_\_\_
- ☐ Heart Health (cardiology): \_\_\_\_\_
- ☐ Maternal Services: \_\_\_\_\_
- ☐ Mental Health & Addictions Services: \_\_\_\_\_
- ☐ Neurosciences: \_\_\_\_\_
- ☐ Oncology: \_\_\_\_\_
- ☒ Palliative Care: **All Services, disbursement of recruitment material, participating in interview/focus group**
- ☐ Rehabilitation: \_\_\_\_\_
- ☐ Surgery Services (e.g. OR/PACU/PAC/SDS/surgical ward): \_\_\_\_\_

**Community Services:**

Not applicable ☐

- ☐ Chronic Disease Management: \_\_\_\_\_
- ☐ Continuing Care & Seniors Health (Special Care Homes – including SHR affiliates): \_\_\_\_\_
- ☐ Home Care/Podiatry/ Client Patient Access Services: \_\_\_\_\_
- ☐ Integrated Community Services: \_\_\_\_\_
- ☐ Mental Health & Addictions Services: \_\_\_\_\_
- ☐ Primary Health Services: \_\_\_\_\_
- ☐ Population & Public Health: \_\_\_\_\_
- ☐ Rehabilitation Services: \_\_\_\_\_
- ☐ Renal Services: \_\_\_\_\_
- ☐ Rural Health Services: \_\_\_\_\_

**Interprofessional Practice/Practitioner Affairs**

Not applicable ☐

Applicable for studies involving health care professionals as study participants, providing therapeutic services/data or as part of the research team.

- ☐ Audiology: \_\_\_\_\_
- ☐ Clinical Health Psychology: \_\_\_\_\_
- ☐ Clinical Nutrition: \_\_\_\_\_
- ☐ Nursing: \_\_\_\_\_
- ☐ Occupational Therapy: \_\_\_\_\_
- ☐ Pharmacy: \_\_\_\_\_
- ☐ Physicians (Practitioner Affairs): \_\_\_\_\_
- ☐ Physiotherapy: \_\_\_\_\_
- ☐ Respiratory Therapy: \_\_\_\_\_
- ☐ Social work: \_\_\_\_\_
- ☐ Speech Language Pathology: \_\_\_\_\_
- ☐ Therapeutic Recreation: \_\_\_\_\_
- ☐ Other (specify): \_\_\_\_\_

**Administration:**

Not applicable ☐

Applicable for studies involving staff as study participants, providing services/data or as part of the research team.

- ☒ Specify: **senior management, participating in focus group**

#### **Part 4: Department Approval**

Please refer to the Operational Approval Guidance notes for the list of Saskatoon Health Region department Managers/designate or contact the Research Approval Coordinator at (306)655-1442.

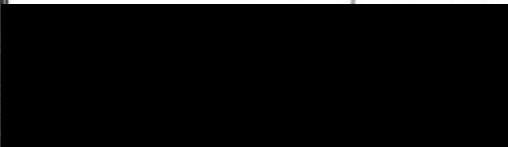
- ☐ Indicate which departments and sites are affected and/or impacted by this study.
- ☐ Indicate the name of the person with whom you have discussed the study
- ☐ **Obtain the signature or email of the SHR Manager or designate indicating his/her approval to proceed. Please contact the Research Approval Coordinator if you require assistance.**
- ☐ Include a copy of any study budget information provided by SHR departments with this application form. Operational Approval will not be provided until all SHR departmental budgets are received.

**\*\*You may use more than one SHR departmental approval page when obtaining approvals\*\***

**Please Note:** SHR operational approval will be granted once all required SHR approvals have been received AND a copy of the U of S ethics application and the U of S ethics certificate of approval have been received.

### SHR DEPARTMENTAL APPROVAL LIST

**IMPORTANT NOTE:** Your approval indicates that you acknowledge and accept the impact (clinical, financial, or otherwise) of the above mentioned research study on your department/division/program.

Department/Program	Affected/ impacted department – division/site	Name(s) and title(s) of Person(s) with whom project has been discussed	Department Approval	
			Approval Signature Or Attach/Forward Email from the Manager's SHR Email Account Indicating Approval	Date (dd/mm/yy)
AMBULATORY SERVICES	_____	_____		
HEALTH RECORDS	_____	_____		
SHIPS	_____	_____		
HEART HEALTH DIAGNOSTIC SERVICES (e.g. cath lab/non- invasive cardiology)	_____	_____		
LABORATORY MEDICINE : specify division (e.g. Chemistry/Phlebotomy, Pathology, LIS, Microbiology, Transfusion Medicine, Cytogenetics)	_____	_____		
	_____	_____		
	_____	_____		
	_____	_____		
MEDICAL IMAGING/ NUCLEAR MEDICINE	_____	_____		
SPECIAL SERVICES PHARMACY	_____	_____		
Please specify program/dept: _____	_____	_____		
<u>Palliative Care Services</u>	<u>SPH, Homecare</u>	<u>Meredith Wild</u>		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		
_____	_____	_____		

**Project Title:** Clear Policy, Clear Conscience: Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

**Principal Investigator:** Dr. Keith Walker Ethics/Protocol #:15-17





UNIVERSITY OF  
SASKATCHEWAN

Associate Vice-President Research – Health  
(University of Saskatchewan)  
Vice-President Research and Innovation  
(Saskatoon Health Region)  
Room A102, Health Sciences Building  
107 Wiggins Road, University of Saskatchewan  
Saskatoon, SK S7N 5E5  
Phone: (306) 966-8745

**DATE:** May 6, 2015

**TO:** Dr. Keith Walker  
Johnson-Shoyama Graduate School of Public Policy  
University of Saskatchewan

**FROM:** Martha E. (Beth) Horsburgh  
Associate Vice-President Research – Health (University of Saskatchewan)/  
Vice-President Research & Innovation (Saskatoon Health Region)

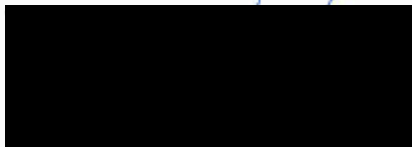
**RE:** **RESEARCH ETHICS BOARD (REB): BEH-15-17**  
**PROJECT NAME: Clear Policy, Clear Conscience: Informing Policy Creation**  
**through an Analysis of the Deliberative Processes of Palliative Care**  
**PROTOCOL #: N/A**

---

Saskatoon Health Region is pleased to provide you with operational approval of the above-mentioned research project.

Kindly inform us when the data collection phase of the research project is completed. We would also appreciate receiving a copy of any publications related to this research. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Health Region.

We wish you every success with your project. If you have any questions, please feel welcome to contact Shawna Weeks at 656-1442 or email [shawna.weeks@saskatoonhealthregion.ca](mailto:shawna.weeks@saskatoonhealthregion.ca)



Associate Vice-President Research – Health (University of Saskatchewan)/  
Vice-President Research & Innovation (Saskatoon Health Region)

cc: Meredith Wild, Manager, Palliative Care, SPH

*Catalyzing Health Research and Innovation Together*

## What can the Health Region learn from you?



"OK, all those in favour of delegating  
decision-making, shrug your shoulders"

**Palliative care staff members needed for research on  
the palliative care approach to healthcare decision-making**

*Participants are invited to a 1-hour individual interview.*

***To join this study, contact:***

**Mary Deutscher, PhD candidate**

**[mkd497@mail.usask.ca](mailto:mkd497@mail.usask.ca)**

**c. (306) 717-6167**

**Project Title:** Informing Policy Creation through an Analysis of the Deliberative Processes of Palliative Care

The choice to participate in this research is voluntary  
and will have no bearing on your employment or professional standings.

Although your answers may be quoted in future publications and presentations, your name and all other identifying information will not be linked to these quotes. Details regarding anonymity, confidentiality, and withdrawal will be provided to participants.

This project has received ethics approval from the Research Ethics Office of the University of Saskatchewan and operational approval from the Saskatoon Health Region





Deutscher, Mary

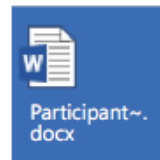
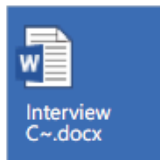
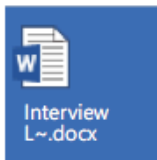
Thu 6/30/2016 9:13 PM

Mark as unread

To: Radcliffe, Beryl;

Cc: Walker, Keith;

📎 4 attachments



[Download all](#)

Hello Beryl,

I am nearing the end of my PhD research, and I just wanted to fill you in on a few minor changes to my project. I hope you can kindly attached the following changes to the file records:

1. I interviewed 12 participants and 1 withdrew, leaving data from 11 interviews for this project. My initial application stated there would be 10 participants.
2. I conducted 2 interpretive panels instead of the originally stated 1 interpretive panel. Recruitment details remained the same for both panels.
3. I updated the letters of initial contact and consent forms to reflect these changes (see attached).

Have a wonderful summer!

Mary

**Appendix D:**  
**Saskatoon Palliative Care Services FAMCARE Results**

## FAMCARE Instrument Results

<b>Client</b>	<b>Saskatoon Health Region (SK006)</b>
---------------	--

<b>Report Date</b>	<b>22-Nov-10</b>
--------------------	------------------

Question #	Question Text	Very Satisfied	Satisfied	Undecided	Dissatisfied	Very Dissatisfied
1	The client's pain relief	58.8%	26.5%	5.9%	5.9%	2.9%
2	Information provided about the client's prognosis	44.1%	26.5%	23.5%	5.9%	0.0%
3	Answers from health professionals	47.1%	41.2%	11.8%	0.0%	0.0%
4	Information given about side effects	29.4%	35.3%	23.5%	8.8%	2.9%
5	Referrals to specialists	29.4%	26.5%	41.2%	0.0%	2.9%
6	Availability of a hospital bed	61.8%	26.5%	2.9%	5.9%	2.9%
7	Family conferences held to discuss the client's illness	44.1%	35.3%	14.7%	2.9%	2.9%
8	Speed with which symptoms are treated	44.1%	35.3%	11.8%	2.9%	5.9%
9	Doctor's attention to client's description of symptoms	41.2%	44.1%	11.8%	0.0%	2.9%
10	The way tests and treatments are performed	41.2%	38.2%	14.7%	5.9%	0.0%
11	Availability of doctors to the family	38.2%	35.3%	23.5%	0.0%	2.9%
12	Availability of nurses to the family	82.4%	8.8%	5.9%	0.0%	2.9%
13	Coordination of care	50.0%	41.2%	5.9%	0.0%	2.9%
14	Time required to make a diagnosis	23.5%	35.3%	35.3%	0.0%	5.9%
15	The way the family is included in treatment and care decisions	47.1%	32.4%	11.8%	5.9%	2.9%
16	Information given about how to	58.8%	20.6%	17.6%	0.0%	2.9%

	manage the client's pain					
17	Information given about the client's tests	35.3%	14.7%	38.2%	8.8%	2.9%
18	How thoroughly the doctor assess the client's symptoms	41.2%	32.4%	20.6%	0.0%	5.9%
19	The way tests and treatments are followed up by the doctor	35.3%	23.5%	32.4%	5.9%	2.9%
20	Availability of the doctor to the client	41.2%	35.3%	17.6%	2.9%	2.9%